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What do you mean, I have a right to health?

Participatory action research on

health and human rights

Jaan Abdulkadir, Amal Azzudin, Alan Buick, Lisa Curtice, Mhurai Dzingisai, Duncan Easton, Claire Frew, Jenn Glinski, Derek Holliday, Lee Knifton, Douglas McLaughlin, Neil Quinn, David Ramsay

In their own words

"The decision is made for you, before you walk into that surgery."

Person with experience of homelessness

"Everyone talks about, you have a right…You have a right to this in the UK, you have a right to that… where is it?"

Woman refugee/asylum seeker

"I really enjoyed my role [facilitating]; it has opened my eyes up more than I thought. It is amazing that society as a general isn't kind to those with addictions and detrimental poor health and homelessness. They are smart, knowledgeable and very resilient, the landscape just doesn't give them equal rights."

Peer researcher

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Executive summary

Background

What does the right to health mean to people who face inequalities and may struggle to access support? This is a pressing issue in Scotland where there is a national commitment to human rights, but where deep seated health inequalities are a major public health concern. The right to the highest attainable standard of health is recognised within the European Convention on Economic, Social and Cultural Rights and should be equally available, accessible, acceptable and of good quality to everyone.

Scotland's National Action Plan for Human Rights (SNAP), launched on 10th December 2013 (International Human Rights Day) has an Action Group on Health and Social Care. This group wanted to hear from people who struggle with difficult life circumstances about what the right to health might mean for them. The purpose was to inform policy makers on the responses needed for everyone to have the opportunity to realise their right to health and to show how taking human rights seriously could improve everyday health and social care practice.

NHS Health Scotland funded a small research study to look at this question. The work was carried out as a partnership between the Centre for Health Policy, University of Strathclyde, the Health and Social Care Alliance Scotland, the Mental Health Foundation and Glasgow Homelessness Network. The research was participatory. Peer researchers from amongst the communities being asked to take part were part of the team that did the research.

The research focused on two groups of people who experience barriers to having the best health they could: people with experience of homelessness and women

asylum seekers and refugees. Homeless people experience poorer physical and mental health than the general population, made worse by continuing homelessness, insecure poor living conditions and stigma and discrimination. Mental ill health, alcohol abuse and substance misuse are the most common health needs. Homeless people also have a much higher risk of death. They also face barriers to accessing healthcare. In one study less than half the homeless participants reported having a family doctor.

Asylum seekers and refugees experience poorer mental, physical and social wellbeing than the general population and they also experience social conditions such as poverty and isolation that are more likely to lead to ill-health. In addition to experiencing health conditions that may be more common in their country of origin, they will be affected by the process of forced migration and the conditions they experience in the host country. Symptoms of depression, anxiety and agoraphobia may result from the stress of bereavement or displacement. Barriers to accessing health care include the problems of navigating the system and access to interpreters. In the UK failed asylum seekers may have treatment withheld because they are required to pay, but cannot afford to do so.

Methods

Five different settings were identified for each arm of the study where it would be possible to speak to people in a range of circumstances. The main method was focus group discussions, although with people experiencing homelessness individual interviews were also conducted and in two of the five settings only individual interviews were conducted. Discussion sessions lasted between one and two and a half hours. Questions covered understanding of the right to health, experiences of services and health issues. The discussion was shaped around the PANEL principles of a human rights-based approach (participation, accountability, non-discrimination, empowerment and legality). Participants were

invited to select and talk about a picture card that illustrated what the right to health meant to them.

The values of participation and empowerment underpin a human rights-based approach. Therefore a participatory approach was adopted for this research. Peer researchers were recruited through the Glasgow Homelessness Network and the Mental Health Foundation. The peer researchers were given training and support, assisted in developing the questions to be asked, led the facilitation of the focus groups and conducted the individual interviews. They commented on the findings and recommendations. The presence of the peer researchers encouraged participation in the groups and the peer researchers reported gaining in skills and confidence from taking part. Throughout the study, the partner organisations, including the peer researchers, worked as a team, collaborating at all stages of the research process, including the dissemination of the findings.

Between December 2015 and January 2016, 34 people who had experience of homelessness and 49 women with the status of refugees or asylum seekers took part in the research in Glasgow, 83 people in total. The groups and interviews with people who had experienced homelessness represented a range of experiences including people sleeping rough, in temporary accommodation, with mental health and addiction needs and preparing to move into an independent tenancy. The women refugees and asylum seekers were aged between 20 and the early fifties; many cared for children. Of those providing the information, 21 identified as of African ethnicity and five as Arab.

Findings

<u>Overall</u>

- **Human rights** felt far removed from participants' reality, but for different reasons. The women's groups compared their current status and fulfilment of rights to that of their origin countries. Although their lives have improved, they did not believe that their rights were being fulfilled. They believed they were treated as second-class citizens and that the government was in charge of who was 'worthy' of rights and who was not. The homelessness groups did not connect with the idea of human rights and believed that the concept had nothing to do with their lives and that, if it did, then they did not know how to claim or engage with the concepts.
- **Mental health** is not addressed appropriately for either group. Both groups were persistent in explaining the overall impact their respective experiences had on their mental health and therefore on their overall wellbeing. It was largely believed that mental health was completely overlooked or treated inappropriately.
- **Discrimination** appeared at all levels of society. This was particularly relevant in the homelessness groups where actions such as phone call to a GP surgery could result in direct discrimination, due only to the sound of the person's voice. Discrimination appeared pervasive throughout the entire homelessness experience and at all levels of society. Unfortunately, it was believed that GP practices and hospitals reflected society's greater discrimination of homeless people, rather than providing a judgement free space.
- **Racism and Islamophobia** were a serious concern for the women taking part in this research study. It was believed that Islamophobia was at an all-time high and prevented women from seeking proper treatment, largely due to their form of dress revealing their religious beliefs. There was a

serious concern for the children of the women who participated in the research and it was stressed that the wellbeing of the children was directly linked to the health and wellbeing of the women.

Key findings with homeless participants

- Overwhelmingly, the responses to the right to health and health services for the homeless population were quite negative.
- Nearly every participant felt discriminated against and made to feel like a second-class citizen with no chance to participate in their own health.
- Dignity and respect were things that were rarely experienced whilst homeless.
- Experiences of stigma and negative stereotypes were common for all participants. This also led to the belief that homeless persons were treated as a group, instead of as individuals with individual needs.
- Participants were very aware of how their circumstances affected their health and understood the impact that housing, safety, and quality of food had on their health and wellbeing.
- Mental health was a serious concern for almost all participants. It was believed that persons experiencing homelessness and suffering from mental health issues did not receive proper treatment and options to improve health.
- The value of lived experience was stressed throughout all the focus groups and participants believed that health services would greatly benefit from training with a person who has experienced homelessness.
- Poor access and quality of information was a significant problem. Participants felt that they did not know much about their rights or entitlements and that they were purposely kept in the dark about them.

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- Making complaints was regarded as very complex (too many forms) and futile as it was believed that nothing would come of complaining. Many did not know how to complain or saw it as a waste of time, if they were familiar with complaints procedures.
- Human rights and the right to health was seen as quite far removed in the focus groups. They were thought of as applicable to developing countries, but not Glasgow. Participants did not believe human rights applied to them or know where to claim their rights.

Key findings with refugee and asylum-seeking participants

- Positive feedback on information had been provided upon arrival to the UK (people know where to go and how to locate their GP).
- The support networks available (women's organisations) are good and very helpful, supplying information and providing support.
- The majority of participants were pleased with their GP and health care services.
- The impact that seeking asylum and living as a refugee in Scotland has on a person is not addressed properly (trauma, mental health, emotional wellbeing, etc.)
- Racism and Islamophobia are serious concerns within health care provision. This is less a systemic issue than a problem at the individual level (individual receptionists, individual GPs, hospital staff, etc.)
- Participants believed that they faced discrimination for being a refugee or asylum seeker and often felt as if they were blamed for their status, instead of treated with respect and as a vulnerable person.
- Language presented a barrier and there are ongoing complications with interpreters (trust issues, community members, not receiving one, being given one despite asking not to)

- Making complaints is difficult and undesirable. Women fear any negative impact on their status and believe complaining will not result in anything substantial. Many also did not know how to initiate a complaint.
- Human rights were understood and recognised, but the majority of participants felt as if their human rights were violated/ not taken into consideration/ not fulfilled.

Recommendations

A number of key recommendations emerge from the findings of this study, which have implications for policy makers and service providers. Several of these are quite specific and relate to enhancing the PANEL themes:

Participation
- Promote volunteering opportunities, especially for those who have experienced homelessness.
- Provide advocacy support in to help people know their rights.
- Promote the participation of people with lived experience of homelessness and other forms of exclusion in NHS staff training and conferences.
- Mainstream the training and employment of peer workers within services.
- Provide information packs to all new patients registering with a GP that inform people of their rights and the care they are entitled to.

Accountability
- Provide feedback forms at primary care services which can be completed anonymously and without having to request them from the receptionist, voluntary providers etc.
- Promote awareness of complaints process amongst people with lived experience of homelessness and the provision of advocacy support in making complaints.

<u>Non-Discrimination</u>

- Challenge racism and religious prejudice, especially Islamophobia, within NHS services and via opinion formers and the media.
- Tackle discrimination and stigma through training led by people with lived experience and strengthen complaints processes, learning from other areas such as mental health stigma programmes.
- Provide training to NHS staff on the impact of asylum seeking on health, including specific training to GPs on dealing with trauma.
- The impact of asylum system on mental health needs to be acknowledged and addressed by Home Office.

<u>Empowerment</u>

- Promote knowledge of rights and how to claim rights – this information must be made accessible and engaging as currently it is not.
- Make the language of human rights more accessible and demonstrate how people can utilise the concepts in everyday life.
- Extend and sustain funding for women's support groups and organisations.

And identify and test potential service improvements which can be summarised under the AAAQ framework, for example:

Availability

- Longer appointments for those with complex needs to provide the opportunity for more person centred practice.

Accessibility

- Improve access to information, including information about rights, through the provision of a one-stop shop and signposting by health, social care and housing practitioners.

Acceptability

- Improve practice on the use of interpreters so people get the assistance they want.

Quality

- Develop better mental health outreach support for people with lived experience of homelessness.

The project steering group will work with NHS Health Scotland and Scottish Government to ensure the research informs future policy and strategy on health and human rights in Scotland and will make connections with international work in this area.

Introduction and background

The purpose of the research was to provide evidence of what the right to health might mean to people from marginalised groups who experience health inequalities. The setting was Scotland and the context Scotland's National Action Plan for Human Rights (SNAP) which was launched on International Human Rights Day, 10 December 2013. The idea for the research was developed through a partnership between NHS Health Scotland, The Centre for Health Policy, University of Strathclyde and the Health and Social Care Alliance Scotland (the ALLIANCE) who were all partners in the SNAP Action Group on Health and Social Care. The rationale for the project was to raise awareness of human rights-based approaches in order to achieve greater consistency of practice and develop a shared, practical sense of what human rights means for day to day practice.

The partners felt that there was a gap in understanding human rights and their implications for improving health and social care from the perspectives of people who were likely to experience barriers in accessing their rights. This is particularly significant in the light of the persistence of deep seated health inequalities in Scotland (Audit Scotland 2012). Reducing health inequalities and promoting equality of access to, and outcomes from, service provision are priorities for Scottish Government.

Based on the feedback from the discussion at the SNAP group, a proposal was developed and NHS Health Scotland agreed to fund a research project looking at groups who may struggle to achieve equal rights of access to health services or to good health due to the health conditions that they experience and/or social conditions and circumstances that are unequal and disadvantageous to health status and access.

It was intended that this would be a participatory action research study to explore three interrelated questions:

- What does a human rights approach to health mean to me/us?
- What are the barriers to, and enablers of, human rights in relation to the PANEL principles of: participation, accountability, non-discrimination, empowerment and legality?
- How can we enable meaningful participation of marginalised groups in health?

The right to health for marginalised groups

The right to health – origins

The right to health is a fundamental part of our human rights and of our understanding of a life in dignity. Internationally, it was first articulated in the 1946 Constitution of the World Health Organization (WHO), that defines health as "a state of complete physical, mental and social wellbeing and not merely the absence of disease or infirmity" and states that "the enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (Hunt and MacNaughton 2006).

The 1948 Universal Declaration of Human Rights also mentioned health as part of the right to an adequate standard of living (art. 25) (UN 1998). The right to health was recognized as a human right in the 1966 International Covenant on Economic, Social and Cultural Rights. Since then, other international human rights treaties have recognized or referred to the right to health or to elements of it, such as the right to medical care.

International human rights law is a set of legal standards to which governments have agreed with the purpose of promoting and protecting these rights (Braveman and Gruskin 2003). International treaties not only prohibit direct violations of human rights but also hold governments responsible for progressively ensuring conditions to enable individuals to realize their rights as fully as possible. Every country is now party to at least one treaty encompassing health-related rights and is therefore responsible for reporting periodically to an international monitoring body on its compliance (Tomasevski 1995, UN 1966). In recent years, increasing attention has been paid to the right to the highest attainable standard of health, for instance by human rights treaty monitoring

bodies, by WHO and by the Commission on Human Rights (now replaced by the Human Rights Council), which in 2002 created the mandate of Special Rapporteur on the right of everyone to the highest attainable standard of physical and mental health (WHO 1946, UN 1966, UN Committee on Economic, Social and Cultural Rights 2000). The right to health, i.e. the right to the highest attainable standard of health makes governments responsible for the prevention, treatment and control of diseases and the creation of conditions to ensure access to health facilities, goods and services required to be healthy (Kirby 1999, Leary 1994). Because all human rights—economic, social, cultural, civil and political— are considered interdependent and indivisible (UN 1948), governments are accountable for progressively correcting conditions that may impede the realization of the "right to health", as well as related rights to education, information, privacy, decent living and working conditions, participation, and freedom from discrimination (Eide 1995). Systematic attention to this range of rights by the health sector can provide a coherent framework for a focus on conditions that may limit people's ability to achieve optimal health and to receive health services (Gruslin and Tarantola 2002).

Key aspects of the right to health

A key aspect of the right to health is that it includes the right not only to health services, but to the wide range of factors which help us to achieve the highest attainable standard of health. These are often referred to as the 'underlying determinants of health'. This shows how mutually dependent human rights are; barriers to good health often impact on access to other rights such as the right to education or work. The Committee on Economic, Social and Cultural Rights identifies that the right to health is inclusive and encompasses both freedoms and entitlements (UN Committee on Economic, Social and Cultural Rights 2000):

The right to health is an inclusive right: we frequently associate the right to health with access to health care and the building of hospitals. This is correct, but the

right to health extends further. It includes a wide range of factors that can help us lead a healthy life. The Committee on Economic, Social and Cultural Rights, the body responsible for monitoring the International Covenant on Economic, Social and Cultural Rights, calls these the "underlying determinants of health". They include:

- Safe drinking water and adequate sanitation;
- Safe food;
- Adequate nutrition and housing;
- Healthy working and environmental conditions;
- Health-related education and information;
- Gender equality.

The right to health contains freedoms: These include the right to be free from non-consensual medical treatment, such as medical experiments and research or forced sterilization, and to be free from torture and other cruel, inhuman or degrading treatment or punishment.

The right to health contains entitlements including:

- The right to a system of health protection providing equality of opportunity for everyone to enjoy the highest attainable level of health;
- The right to prevention, treatment and control of diseases;
- Access to essential medicines;
- Maternal, child and reproductive health;
- Equal and timely access to basic health services;
- The provision of health-related education and information;
- Participation of the population in health-related decision-making at the national and community levels.

The right to health also contains four inter-related and essential elements: (1) Availability, (2) Accessibility, (3) Acceptability, and (4) Quality (AAAQ). While these essential elements are often described in connection to health care services, programmes and goods, they also apply to the underlying determinants of health. In other words, health care must be available, but safe water and housing must be available too. The AAAQ framework can be summarised in terms of:

1) Availability: Health facilities, goods and services must be available in sufficient quantity. This includes, for example, hospitals, clinics, trained health professionals and essential medicines, as well as underlying determinants, such as safe drinking water and adequate sanitation facilities.

2) Accessibility: Health facilities, goods and services must be accessible to everyone without discrimination, especially the most vulnerable or marginalized people. They must be physically accessible, meaning within safe physical reach of all sections of the population, including people with disabilities and people in rural areas. They must be economically accessible, meaning affordable to all. Moreover, accessibility includes the right to seek, receive and impart information on health.

3) Acceptability: Health facilities, goods and services must be respectful of medical ethics, including the right to confidentiality, and they must be sensitive to cultures, communities and gender. Further, health information must be provided in local languages.

4) Quality: Health facilities, goods and services must also be scientifically and medically appropriate and of good quality. Further, the underlying determinants of health must be appropriate and of good quality too. Thus for example, water and health education, in addition to hospitals and medicines, must be of good quality.

The appointment by the UN of a Special Rapporteur on the right of everyone to the highest attainable standard of health has brought increased attention to making the right to health a reality (Office of the United Nations High Commissioner for Human Rights (OHCHR) 2008). Action to ensure everyone can access the highest attainable standard of health must go beyond health systems. The Special Rapporteur has also set out a number of important factors for all services and public bodies to consider in order to ensure the right to health is explicitly upheld in the planning and delivery of services (Northern Ireland Human Rights Commission):

1) The right to health is subject to progressive realization. Many States do not currently have the resources necessary to implement fully the right to enjoyment of the highest standard of attainable health for all people. Nonetheless, States must take deliberate and concrete steps toward the full realization of the right to health for all. The corollary to the obligation to progressively realize the right to health is that "there is a strong presumption that retrogressive measures taken in relation to the right to health are not permissible".

2) While the right to health is subject to progressive realization, States have a core obligation in relation to the right to health that is immediate, and requires, at the very least, minimum standards of primary health care, food, housing, sanitation and essential drugs. This core obligation also includes adopting and implementing a national health strategy and plan of action. Of comparable priority are reproductive, maternal and child health care; immunization against major infectious diseases; measures to prevent, treat and control epidemics; health education; access to health information; and appropriate training for health professionals.

3) It is important to emphasize that non-discrimination and equality are central to the right to health. The right to health proscribes any discrimination in access to or provision of health care and the underlying

determinants of health. Moreover, special attention must be paid to promoting the equality of women and men and of vulnerable and marginalized groups. Indeed, careful consideration of health resource allocations is required to ensure that health policy and spending promotes equality rather than contributing to or perpetuating inequalities.

4) A further important aspect of the right to health is the participation of the population in all health-related decision-making at the community, national and international levels. Participation implicates, among other factors, the rights to seek and impart health-related information, the right to express views freely, and the right to basic health education, as well as transparency in policy-making processes. Full participation on a non-discriminatory basis also requires special attention to sharing information with and seeking the views of women and men, as well as the views of vulnerable and marginalized people.

5) Access to health information is also an essential aspect of the right to health. Health information enables people to promote their own health and to claim quality health facilities, goods and services from the State and others. Therefore, States must ensure that health information is available and accessible to all, and that it is provided in local languages. The right to health also includes the freedom of all people to seek, receive and impart information concerning health issues. Indeed, other essential aspects of the right to health, such as meaningful participation and effective accountability, depend upon having access to information, as well as the right to express views freely. While health information must be made available, personal health data must be treated with confidentiality.

6) The right to health demands access to effective mechanisms of accountability, including judicial remedies at both the national and international levels. Victims of violations of the right to health are "entitled to adequate reparation, which may take the form of restitution, compensation, satisfaction or guarantees of non-repetition". In addition to

judicial remedies, national ombudsmen and human rights commissions should also address violations of the right to health.

The right to health in Scotland

Human rights arise from a variety of sources, including international and domestic law (Wilson and McIlwhan 2010).

Health boards and other public authorities have legal obligations arising from the Human Rights Act 1998, which requires all public authorities to respect and protect the rights contained in the European Convention on Human Rights (ECHR), on which the Human Rights Act is based. These rights include: the right to life; to be free from inhuman or degrading treatment; to liberty; to privacy and family life; and to be free from discrimination. Some of these rights not only require public authorities to protect the rights, but also to take positive steps to promote them. For example, a health board would have to ensure that not only did it not actively end a life, but also that it took appropriate steps to protect life, e.g. through provision of treatment or care.

Rights protected under the Human Rights Act can be enforced in UK courts, whereas rights enforced through the ECHR must be enforced in the European Court of Human Rights. Whilst most of the rights in the ECHR are included in the Human Rights Act, some are not. For example, article 1-the obligation to respect human rights, and article 13 –the right to an effective remedy, must still be enforced through the European Court of Human Rights.

Human rights have a special position in Scottish law. Not only do the UK Human Rights Act 1998 and the European Convention on Human Rights apply in Scotland as they do elsewhere in the UK, but the Scotland Act 1998 provides that the Scottish Parliament cannot create law that is incompatible with the

ECHR, nor can the Scottish Government take any action, or inaction, which might breach those rights.

The Scotland Act also specifies that the Scottish Parliament must ensure compliance with international obligations. These obligations would include all obligations arising from international human rights treaties to which the UK is a signatory. These include:

- Universal Declaration on Human Rights
- International Covenant on Civil and Political Rights
- International Covenant on Economic, Social and Cultural Rights
- UN Convention on the Rights of the Child
- UN Convention against Torture

There are a number of essential elements to a rights-based approach which will maximise opportunities to improve health and address inequalities. These provide prompts for governments, society, organisations and individuals to consider in the practical application of the right to health. Scotland's National Action Plan for Human Rights (SNAP) was launched by the Scottish Human Rights Commission in December 2013 as a way of advancing a human rights-based approach across a range of policy areas. SNAP draws on international best practice (having worked well in a number of countries including Sweden, Finland, Australia and New Zealand) and is a road-map to make all human rights real. It is based on three key principles - it is evidence based, participatory and independently monitored. The right to health is one of the key commitments of SNAP. A number of groups have been established to support the ambitions set out in the Plan, including a Health and Social Care Action Group co-convened by NHS Health Scotland and the ALLIANCE.

SNAP promotes the PANEL principles as a way for the public sector, the third sector, communities and individuals to put rights into practice (Scottish Human Rights Commission undated). The PANEL principles of a human rights-based approach are:

Participation – people take part in decision making and have a voice;
Accountability – organisations and people need to be more accountable for realising human rights;
Non-discrimination – everyone has the same rights (regardless of their ethnicity, gender, income, religion for example);
Empowerment – to give power to people to know and claim their rights in order to make a difference;
Legality – to make sure all decisions answer to human rights legal standards.

SNAP has been developed against a background of rising health inequalities in recent years. Inequalities in health, between the most and least privileged people and communities, are clearly apparent in Scotland. In 2009/10, for example, life expectancy at birth for men was 69 years for the most deprived 10th of the population compared to 82 years for the least deprived 10th, a difference of 13 years. The difference in healthy life expectancy was even starker, at 47 years for men in the most deprived 10th compared to 70 years for those in the least deprived 10th, a difference of 23 years. This demonstrates how social inequalities in a range of life chances (early life experiences, education, employment, family life, income and wealth, housing, environmental hazards, etc.) can become literally 'embodied' and shape people's health and longevity (Beeston et al 2014). Despite the vast reductions in mortality in Scotland over the last 150 years, overall life expectancy remains lower, and average mortality remains higher, in Scotland compared to the rest of west and central Europe (McCartney 2012). Even within Eastern Europe, deprived de-industrialised regions are improving more rapidly than the similarly de-industrialised area

around Glasgow. Within Scotland, mortality inequalities between those with the most and least education are higher than in the rest of west and central Europe amongst men (Schofield et al 2016).

Homelessness and the right to health

A group that experiences particular challenges in realising its right to health is people who are homeless. A number of international studies suggest homelessness is associated with poor health outcomes with homeless individuals experiencing significant physical, mental health and substance abuse issues (Weber et al 2013). Specific problems include substance abuse, HIV/AIDS, mental disorders, and dental, dermatological, and gastrointestinal problems (Aguiar and Iriart 2012).

These international studies are supported by evidence from the UK. Homeless people experience poorer physical and mental health than the general population (St. Mungo's 2013, Scottish Government 2005). As shown in Table 1, a 2014 health audit of over 2500 homeless people found much higher prevalence of physical, mental and substance misuse issues in the homeless population compared to the general population (Homeless Link 2014).

Table 1

Health Issue	Homeless Population	General Population
Long term physical health problems	41%	28%
Diagnosed mental health problems	45%	25%
Taken drugs in the past month	36%	5%

Homeless people have a much higher risk of death from a range of causes than the general population (Morrison 2009). A retrospective five year study in Glasgow found that being homeless increases the risk of death from drugs by seven times, trebles the risk from chest conditions and doubles risk from circulatory conditions. Many of the health conditions that homeless people develop in their 40s and 50s are more commonly seen in people decades older. The average age of death for a homeless male person is 47 compared to 77 in the general population (Crisis 2011).

The most common health needs of homeless people relate to mental ill-health, alcohol abuse and illicit substance use and dual diagnosis is frequent (Wright and Tompkins 2006, Wang and Burns 2014). Violence such as injuries and assaults are also a threat to the physical and psychological health of homeless people (Hwang 2001, Fazel, Geddes and Kushel 2014). Depression and suicides are higher among homeless people compared to the general population. Mental ill health is both a cause and a consequence of homelessness as are alcohol and substance abuse (Edidin, Ganim, Hunter and Karnik 2013, Wang and Burns 2014). There is also a complex relationship between homelessness and offending with an increase in the risk of homelessness for those who have spent time in prison and a lack of stable accommodation increasing the risk of (re)offending (Dore 2005).

In summary, the research indicates that homeless households experience poorer physical and mental health, which can be exacerbated by continuing homelessness and insecure, poor living conditions and stigma/discrimination. Mortality rates are higher, highlighting the extreme health inequalities experienced by this group.

Against this backdrop of poor health outcomes, several studies point to the barriers to accessing health care experienced by homeless people. Having a

family doctor seems a particular challenge, with one study finding that less than half of the homeless participants reported having a family doctor, which was associated with key indicators of health care access and health status, including increasing duration of homelessness and increased likelihood of having a chronic medical condition (Khandor et al 2011). Related to this, other studies have found that homeless women are more likely to use emergency rather than primary care services (Vijayaraghavan et al 2012). There is also evidence of homeless people having unmet medical needs that result in them having worse health status - a lifetime burden of chronic conditions, mental health problems, and substance use problems (Lebrun-Harris et al 2013).

This suggests that homeless people are therefore not enjoying the right to the highest attainable standard of health, a right recognised within the European Convention on Economic, Social and Cultural Rights, and that there is a need to ensure that the right to health is equally available, accessible, acceptable and of good quality to people experiencing homelessness.

Asylum seekers and refugees and the right to health

Migration has become a major political, social and economic phenomenon, with significant human rights consequences. Evidence suggests asylum seekers and refugees experience specific challenges in relation to the right to health.

In almost all indices of physical, mental, and social wellbeing, asylum seekers and refugees suffer a disproportionate burden of morbidity (Walker and Jaranson 1999, Dick 1984, Burnett and Peel 2001a, Burnett and Peel 2001b). The health effects of the immigration process may be considered in terms of the past and present consequences of forced migration. For this group, there is an unequal distribution not only of ill-health but also of the social determinants of ill-health (including poverty, social isolation, literacy, self-efficacy, and so on). It is generally agreed that there is a reciprocal relationship between ill-health and

these wider determinants (Evans, Barer and Marmor 1994). This is a crucial point in considering how to reduce health inequalities, as it may not simply be a question of providing 'more or better' health care (Evans and Stoddart 1990).

Physical health needs of migrants tend to reflect the endemic spectrum of disease in their home country. Thus, infectious diseases including HIV, tuberculosis, malaria, and other parasitic diseases are often more prevalent among immigrants from sub-Saharan Africa (Walker and Jaranson 1999, Dick 1984). In many refugees from eastern Europe, higher rates of chronic disease, including diabetes and cardiovascular disease, have been reported (Burnett and Peel 2001a) Other problems include poor dentition, malnutrition, and incomplete immunisation. In addition, health behaviour may be affected by forced migration. Several studies have reported a high prevalence of non-specific or somatising presentations as a result of psychosocial distress (Burnett and Peel 2001b).

In terms of psychological health, it is unsurprising that symptoms of depression, anxiety, and agoraphobia have been reported among refugees and asylum seekers (Walker and Jaranson 1999). These symptoms may result from stressors including bereavement, displacement, or torture. Many of these symptoms are further exacerbated by conditions in the host country, including compulsory detention, poverty, unemployment, housing, and social isolation. Different cultures have different models for conceptualising mental health and seeking help, which may complicate the provision of services such as counselling (Bracken, Giller and Summerfeld 1995). Although high rates of post-traumatic stress disorder (PTSD) have been reported (Bison 2007), much of the burden of illness may be beneath the level of formal psychiatric diagnosis (APA 2000). It is paradoxical, however, that those affected may only be able to seek help through a medical system that may stigmatise or label them. A diagnosis of PTSD may be sought in support of an asylum application. Some argue that the solutions to

most psychological distress among refugees require social rather than medical intervention (Burnett and Peel 2001b, Bracken, Giller and Summerfeld 1995).

These poor health outcomes are compounded by barriers to accessing health care. The barriers can be: internal, including mental illness, fatalism, mistrust, and perceived discrimination; structural, including affordability, limited services, inadequate interpretation, resettlement challenges such as shelter, food, and employment insecurity; and in social assimilation, including difficulty navigating a complex system and inadequate community support (Asgary and Segar 2011, O'Donnell et al 2007). Other barriers identified include unemployment, language, lack of health insurance, lack of transportation, distrust of doctors, lack of confidence in speaking English and making phone bookings (Elwell et al 2014, Riggs et al 2012). There appears to be a link between high levels of trauma symptoms among this population with an increased risk for disease and decreased access to healthcare services (Wagner et al 2013). In many countries, asylum seekers and refugees only have access to emergency care, while additional care is restricted and may be subject to payment (Biswas et al 2012). The provision of health information appears to be important in helping asylum seekers and refugees realise their rights (Ekblad, Linander and Asplund 2012). Finally, lack or poor use of interpreting services also seems to be a major barrier to accessing health care for asylum seekers and refugees (Clark et al 2014).

Within the UK, government policy differentiates between access to primary and secondary care, and entitlement to 'routine' or 'emergency' treatment. The government also differentiates between failed asylum seekers and those who are applying for asylum. This two-tier system gives rise to several situations in which care may be deliberately withheld (Taylor 2009). For example, in the case of HIV, failed asylum seekers are entitled to testing and counselling but not to treatment of HIV with antiretroviral drugs. In the case of diabetes, patients may complete a course of treatment for complications but would not be entitled to ongoing care if

their asylum appeal was subsequently unsuccessful. Prior to the recent high court ruling, the government has advised that 'best practice is to ensure that overseas visitors are aware of the expectation to pay charges ... before they start treatment, so they can consider alternatives like a return home, if they are well enough to travel' (Department of Health 2003). Most undocumented and failed asylum seekers will, of course, be unable to pay and in effect will be refused treatment. A further implication of this policy is that the onus is placed on healthcare staff to discern a patient's immigration status. Some argue that this places doctors in the impossible position of either breaking the law by maintaining the principles of 'Good Medical Practice' and providing care on the basis of need, or complying with the current political imperative by applying a discriminatory policy (Harding-Pink 2004, Forrest and Barratt 2004).

Conclusions

This review identifies the origins of the right to health within international treaties and the key principles which inform how this right can be realised in practice. The elements of a human rights-based approach to health within a Scottish context are outlined, within the context of Scotland's National Action Plan for Human Rights (SNAP). Finally the review focuses on the right to health for two particularly marginalised groups within Scotland – homeless people and asylum seekers and refugees - and considers what this means for these population groups in terms of health of poor health outcomes and barriers accessing services that will improve their health.

What clearly emerges from this study is the need for a better understanding of what the right to health means for marginalised populations in practice within a Scottish context, in order to inform how policy makers in Scotland can more effectively respond to ensure these groups have an opportunity to realise their right to health. The proposed research aims to address this gap in understanding

through participatory research on the right to health by people with lived experience.

Methods

Aims

The aims and objectives of the research were to:
- Recognising the power and resource inequalities that lie at the heart of health inequalities, seek to (a) shift the balance of power and resources so that people have influence and control and their lived experience provides the evidence for tackling health inequalities, and (b) mitigate the negative health impacts of inequality.
- Increase: understanding of 'the right to health'; capacity of rights holders to claim their right to health; and the ability of organisations to adopt a Human Rights-Based Approach (HRBA) and support the realisation of the right to health.
- Influence the policy narrative so that human rights are increasingly embedded throughout health and social care and bring a more robust foundation to ideas such as 'person centredness' and 'participation'.

The research questions were:
- What does a human rights approach mean to me/us?
- What are the barriers to, and enablers of, the human rights principles of availability, accessibility, acceptability and quality of facilities and services, participation, equality and non-discrimination and accountability?; and,
- How can we enable meaningful participation of marginalised groups in health?

Methodology

A participatory research model was adopted because this was consistent with the values of participation and empowerment underlying a human rights-based approach. Participatory action research (PAR) is a process of 'collective, self-

reflective inquiry' (Baum, MacDougall and Smith 2006) that aims to bring about action, values lived experience and should empower participants through their active engagement in research and action. This approach has strong affinities with community based participatory research (CBPR) which involves citizens with different kinds of health conditions (such as mental health problems, addiction issues, HIV) or living in more disadvantaged circumstances (such as on the basis of poverty, gender, migration, unemployment, sexual orientation). A CBPR approach brings together academics, practitioners and citizens jointly to develop, undertake and disseminate research. It is a democratic approach to knowledge generation that acknowledges the insights, skills and expertise that each group can bring to complex health challenges. In this study we sought to engage with people from the relevant communities to act as peer researchers and lead the data collection. By training peer researchers to speak to members of each population we hoped to gain greater access to information on the ground in order to understand where the right to health falls short for vulnerable populations. The participant focus of the research is based on the belief that those who are most vulnerable to health barriers are best placed to provide information on barriers and will interact more willingly with peers than with non-peers.

The peer researchers were supported to make choices of research methods within a qualitative framework. Focus groups were offered as an approach because they enable data to be generated through an interaction between participants and therefore provide insight into the meanings and experiences of people who may share common circumstances (Kitzinger 1994). One-to-one interviews were also included to provide more details of an individual's life story and to provide the option of privacy for people not wishing to share this in a group.

The peer researchers were also encouraged to consider creative methods for data collection and dissemination, including storytelling and digital storytelling.

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The approach chosen for data collection included the use of picture cards to enable peers and participants to reflect on their experiences and understanding of the right to health (NHS Education for Scotland et al undated).

Selection of study populations

We proposed to work with two groups of participants. Engagement with a number of population groups were considered for the research including gypsy travellers, people with experience of the criminal justice system, people with experience of homelessness, asylum seekers and refugees and people with long term conditions. All met the condition of groups who might struggle to achieve equal access to healthcare and/or face significant challenges in accessing the conditions for good health. The research steering group developed the following criteria to identify the two groups that could be invited to take part in the study:

- Community worker involved who could liaise with and support the work;
- A group of action researchers or peers already in existence;
- An organisation with capacity to support them; and,
- Ways to access potential participants.

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· On this basis it was agreed that the research would include people with experience of homelessness and women refugees and asylum seekers. The Glasgow Homeless Network already had experience of participatory research and was running a project, Navigate, to assist people to find services, which had a number of peers with current or recent experience of homelessness who were acting as volunteers to provide information and support to homeless people and who might be willing to participate as peer researchers. The Mental Health Foundation Scotland had supported a group of women asylum seekers and refugees who had been involved in work on mental health and had a development worker with personal and professional experience of the issues

facing those in the asylum system. Female refugees and asylum seekers face greater barriers to accessing healthcare than males and the majority of those accessing services are women.

A research steering group was formed with representatives of all the agencies involved (Appendix A) and a Ph.D. researcher with expertise in human rights[1] employed on a one day a week contract. The researcher explained human rights to the peer researchers, developed interview schedules alongside them, assisted at the focus groups and analysed and drafted findings. The steering group met regularly throughout the research. Members of the steering group also contributed to the research by conducting the literature review, training peer researchers, assisting at focus groups and contributing to the analysis and write up of the research.

Recruitment and training of peer researchers

The first stage of the research process was the recruitment and training of peer researchers. The Glasgow Homeless Network and the Mental Health Foundation spoke to peers with relevant experience who they thought might be interested in taking part. After a preliminary meeting with each group to introduce the research and explain the role of peer researchers, a day of initial training was held, separately for each group (Appendix F and G). This included an introduction to human rights and the PANEL principles. There was also an explanation of the purpose of the present research, the pros and cons of focus groups and interviews, an overview of the stages of the research process, ethics and preliminary discussion of where participants could be found and of possible research questions. During the training, both groups enjoyed the reflective discussion provoked by the use of images and commented that this had helped them to realise both what they had in common but also that a picture could mean

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[1] Jenn Glinski

different things to different people, depending on their life experience. It was therefore agreed to use this approach as part of the research. Following the training and some further meetings, two women from the Mental Health Foundation group (out of an initial cohort of four) and five volunteers from the Glasgow Homeless Network agreed to take on the roles of peer researchers[2].

Methods

The methods and questions were developed with each of the two groups of peer researchers. The GHN group opted for focus groups followed by individual interviews and the MHF group for focus groups. The interviews schedules are attached in the Appendices (B, C and E). Both groups included questions on access to and experience of services as well as experiences of health. Questions were designed to reflect the PANEL principles (participation, accountability, non-discrimination, empowerment and legality). Both groups opted to open the sessions with the use of picture cards, encouraging participants to select and talk about an image that reflected the meaning of the right to health to them[3].

The groups that were invited to take part in the research were selected to reflect a range of relevant life circumstances. Contact with the groups was made by the peer researchers (GHN) and the peer development worker (MHF). Participating organisations were offered expenses. The groups and interviews conducted are shown in Table 2.

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[2] Sadly one of the Navigate volunteers, Donna Houston, who had been involved in all the preparations died before the fieldwork began. One of the women in the other group who did not take part in the research nonetheless took part in a later discussion on recommendations arising from the findings.

[3] We used the Envision cards, copyright NHS Education for Scotland.

Table 2

Group	No. of participants	Description
Glasgow Homelessness Network		
Navigate clients	Focus group: 6 Individual interviews:6	Broad range of participants including some now volunteering, others with more current issues.
Marie Trust	Focus group: 9 Individual interviews: 8	A hostel – people who were currently homeless
Volunteers from Navigate and South East alternatives	Focus group: 4 Individual interviews:4	Volunteers some with experience of addictions
Aspire	Individual interviews: 10	Emergency accommodation
Arch	Individual interviews: 5	Resettlement – people ready to move
Mental Health Foundation Scotland		
Maryhill Integration Network	17	Community network for asylum seekers and refugees
Saheliya	11	Specialist support project for minority ethnic women
Saheliya	9	Specialist support project for minority ethnic women
Scottish Refugee Council	4	Women's Strategy Group
Craigton/Govan Integration Network	8	Community network for asylum seekers and refugees

The sessions took place between December 2015 and January 2016 and lasted between one and two and a half hours. Questions were led by the peer researchers who began by explaining their own experience and why they had volunteered to take part in the research. The purpose of the study was introduced and the participant information sheet was explained, in particular that participation was entirely voluntary and people could withdraw at any stage. All groups were audio recorded and noted; most one-to-one interviews were recorded by notes only. At the end of the research session participants were asked to complete a short, anonymous form to provide demographic details. The GHN peer researchers completed debrief forms themselves at the end of the sessions, highlighting the themes they had noticed and their own impressions and learning.

Ethics

Ethical permission for the research was obtained from the Research Ethics Committee of the University of Strathclyde who approved the approach and the participant information and consent forms. The main ethical challenges identified for this study related to the vulnerability of participants. The research team was aware that participants might be in precarious life circumstances. By having as partners in the research two organisations that were able to offer support to participants, if required, we ensured that if any issues were raised that required immediate support, participants could be directed to appropriate information and support. During the research sessions the peer researchers also made sure that participants were not merely asked for information, but were told that they had human rights. Ethical issues were also identified in respect of the peer researchers who might hear distressing stories and were being asked to take on a new role of researcher, rather than advocate. This was addressed through training, continuous support and discussion and by always working as a team.

The researchers supported each other and had existing skills and experiences to draw upon themselves to handle the groups and interviews.

All participants had a verbal explanation of the written participant information form (through an interpreter where necessary) and the opportunity to ask questions before completing a consent form. Consent forms were completed before any data collection started in the sessions. Participants were told about the purpose of the research; confidentiality and anonymity was explained and the groups were also requested to respect confidentiality. Confidentiality was especially important to women asylum seekers and refugees who might be concerned that what they said could affect their status. Permission was requested for audio recording. All groups agreed to this. All demographic data was obtained anonymously and data have been securely stored. No details have been reported from the groups or one-to-one interviews that might identify individuals.

How the analysis was done

For the groups, recurring key words and themes were identified from the audio recordings and coded.   Illustrative quotes for the themes were transcribed. The themes were displayed on a chart and categorised as positive, negative or neutral (from the perspectives of participants). The display of themes assisted in identifying the frequency of negative/positive/neutral comments for each group. A similar process was followed for the notes taken during the one-to-one interviews. The themes and key words were then mapped across to the PANEL criteria.

A preliminary session on key themes was held with each group of peer researchers and a further follow up session after the report was in draft to consider the summary findings and recommendations. The themes identified chimed with their recollections and understanding and they added comments. A

session where the peer researchers reflected on their experience of the research was held with each group of peer researchers in preparation for a conference workshop about the peer research process.

The total number of research participants was 83 of whom 34 were people who had or were currently experiencing homelessness and 49 were women refugees or asylum seekers. The range of services invited to participate in the research by GHN were chosen to reflect a wide range of experiences of homelessness including people sleeping rough, people living in temporary accommodation, people with wider needs including mental health and addictions and people in more stable circumstances preparing to move into an independent tenancy. All but one of the people experiencing homelessness who took part were men and all the refugee/asylum seeker participants were women. 30 of the women refugees/asylum seekers gave further information anonymously about their age, ethnicity and status. Ages ranged from mid 20s to early fifties; of those providing the information, 21 identified as of African ethnicity and five as Arab (one, White Scottish and three did not answer). The majority (14) described themselves as refugees and five as asylum seekers (six did not answer and five used other terms including EU (3) and 'citizen').

Findings

Persons experiencing homelessness

The peer researchers of the Glasgow Homelessness Network (GHN) conducted focus groups and one-to-one interviews with 34 participants from a variety of homelessness support services throughout Glasgow. This section provides an overview of the key themes that became apparent throughout the data collection process, an explanation of the themes as well as examples and quotes from the participants.
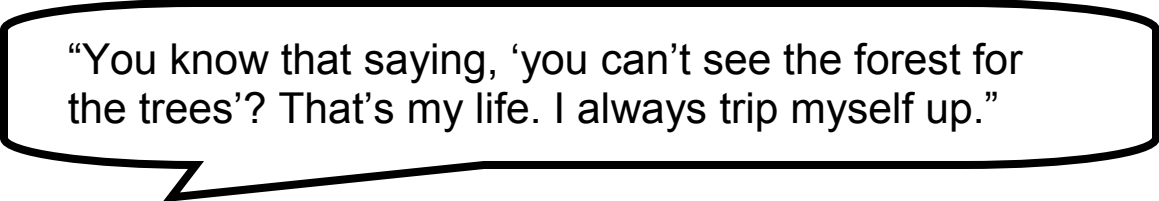
The section begins with an overview of the overall impact of homelessness on health and the perceptions of the right to health among the research participants. It then presents the rest of the themes according to the human rights-based approach (PANEL) structure. We acknowledge that several themes fit under a variety of PANEL headings, although for easy readability we have presented the themes under the PANEL heading which was believed to be most relevant to the research participants. This is not to establish a hierarchy among the PANEL headings, but simply to represent more accurately the way in which participants spoke about the different themes and how they themselves interpreted and categorised them. To assure consistency in human rights research, the PANEL definitions are the same as presented by the Scottish Human Rights Commission and can be found in Scotland's National Action Plan for Human Rights.

Impact of homelessness on health

Throughout all of the focus groups and one-to-one interviews, it was made clear that experiencing homelessness had a severe impact on personal health, both physically and mentally. Not only did homelessness directly impact health, but the challenges associated with homelessness (moving around a lot,

inconsistencies in one's day, needing a postcode to register, etc.) also made it more difficult to seek assistance in maintaining health and wellbeing.
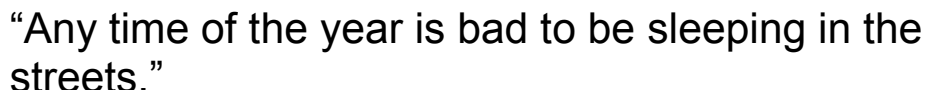
The nature of homelessness

"You know that saying, 'you can't see the forest for the trees'? That's my life. I always trip myself up."

Research participant (Group 2)

One of the things mentioned repeatedly was the lack of control over homelessness and living a "chaotic" life full of uncertainties. Participants spoke about this in great detail in regard to making appointments with a GP, as well as being able to appear on time for scheduled meetings and appointments. Taking medication regularly and as prescribed, as well as being able to rest and recover in a safe environment, were described as difficult to achieve due to the uncertainties of day to day life whilst homeless. Having purpose and structure to daily life was the top health priority identified in one-to one interviews (six out of 62 responses).

The one- to-one interviews revealed that many participants faced substance abuse issues, which most participants were seeking treatment for. Many participants commented that substance abuse commenced during their experience of homelessness and some mentioned it was used as method of self-help. Others felt that substance abuse led to their homelessness. Furthermore, in one-to-one interviews 11 out of 21 comments identified addiction (drink, drugs or both) as an indicator of how they had sacrificed their health. "Quite often the vodka would win", one participant stated in their one-to-one interview. Ten out of 23 identified addiction issues as what had stopped them from getting

accommodation and achieving good health and wellbeing (above waiting lists and lack of services and support, 7, and not understanding the information given, 3).

"Any time of the year is bad to be sleeping in the streets."

Research participant (Group 2)

The impact of rough sleeping was also a frequent topic of discussion. Sleeping on the street had made some participants more vulnerable and more unwell. It was also said that it isolated participants even further from society and compounded their depression. One participant (Group 2) described how he committed a theft, purposely on a Friday, so he could be safe and warm over the weekend. The participant said they thought to themselves, "jail has got to be better than this!" whilst sleeping rough in the streets. Another participant in the same group highlighted an occasion where a street team member provided a sleeping bag whilst they were sleeping in an alley. They responded to the street team member by saying, "but I am still sleeping outside!"

Mental Health

Mental health issues were addressed in great detail in all the focus groups. All participants displayed an in depth understanding of how their status negatively affected their mental health and many saw it as the main obstacle to overcome whilst being homeless. The stigma and negativity surrounding being homeless, lack of physical health and uncertainty of safety were all cited as reasons for experiencing mental health issues. Moreover, many participants felt that health services had a very limited understanding of how to deal with people who were homeless and experienced mental health issues. In the research participants' opinions, mental health played a varied role in homelessness. It could be a

cause, a contributing factor or a result of experiencing homelessness. Regardless of its role, research participants felt strongly about the lack of understanding, treatment and support available for those experiencing homelessness and mental health issues and viewed it as multiple discrimination.

It was pointed out that there is a difference in the way that those with diagnosed mental health issues were treated compared to those with undiagnosed problems. It was commented that, regardless of whether or not the health issue was official or unofficial, it was no less real to those suffering. An example was given of a participant with an undiagnosed mental health issue being housed on the top floor of a building, with complete disregard of what they claimed to be mental health issues. This placement encouraged thoughts of suicide and created tremendous stress for the participant.

In the one-to-one interviews research participants were asked how healthy they felt today. Of 26 comments, seven mentioned mental health issues including anxiety, 'fear of living life', mood swings and depression.

The right to health according to participants

As outlined in the methods section of this report, participants were asked at the beginning of the focus groups to engage with the question, 'what does the right to health mean to you?' Each participant had a selection of picture cards to choose from when deciding what they thought of when they heard the words 'right to health' and 'human rights'. Below is a random sample of picture cards[4] which were chosen and the description of the card as stated by the participant who selected it.

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[4] The cards are the copyright of NHS Education for Scotland, reproduced here with permission.

"You know that saying 'you can't see the forest for the trees'? That's my life. I always trip myself up [...] I'm not unique. There's 1000 that came before me, there's 1000 coming after me."

Research participant (Group 2)

"I am inundated with forms. Try getting help to fill them in. Try finding the right person to help you."

Research participant (Group 1)

In the one-to-one interviews participants were asked about their day-to-day priorities in relation to health. As already mentioned, purpose and a structure to the day came first, along with eating well (six out of 62 responses each), followed by social interaction (five), stopping smoking, addressing addiction issues, going for a walk, volunteering (four each), starting to exercise, seeing relatives, a safe environment, shopping and the gym (three each), remaining sober and clean, music and art, keeping self to self, good sleep, being able to take medication, taking each day as it comes (two each) and mindfulness practice and alcohol. These priorities illustrate the wide range of concerns participants had in relation

to their health, including social as well as lifestyle factors, and their awareness of conditions that contribute to good health and their wish to attain these.

1. 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. (Scottish Human Rights Commission)

<u>Lack of participation</u>

One of the main principles of the human rights-based approach to health is the ability to participate in decisions which are made either for yourself or your community. By promoting a human rights-based approach to health, each person has the right to participate in decision-making processes and for their opinion to be heard and counted without discrimination.

The feeling of being unable to participate in decision-making regarding their health and personal circumstances was a strong theme with which most research participants identified. One participant (Group 1) stated, "I think we're treated as a group…there's no individuality about it." Participants felt that they were not treated with respect as individuals and that even when trying to engage with health practitioners their opinions were ignored. As mentioned above, there was a strong sense that doctors knew what they were going to do with homeless patients the moment that person walked through the door and that there was no room to negotiate, request or provide input for the patients. Several participants mentioned requesting not to be prescribed certain medications due to addiction issues (i.e. sleeping pills, methadone and pain killers) yet said that they were given a prescription for them anyway. As one participant (Group 1) summarised, "we are not listened to and we are not treated with respect".

Many participants felt that there was currently no scope for them to know how to participate in their own health care due to lack of information available from and in primary care, both from GPs and receptionists. It was felt that in many ways participation from persons experiencing homelessness was discouraged because it was assumed that they would not know what was good for them anyway and therefore it should be left to the professional medical staff.
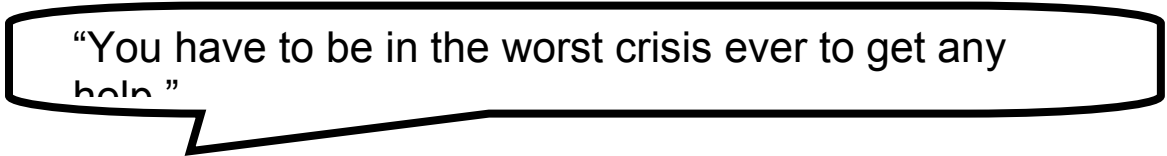
2. Accountability

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 in order to secure human rights. (Scottish Human Rights Commission)

Negative experience of services

Overwhelmingly, the discussion in all focus groups surrounding health services was negative. Almost none of the 34 participants had a positive experience to share about treatment they had received when seeking assistance in health related matters. Although the right to health is not just about health services, the focus group participants often made this a focal point when discussing their experience to the right to health.

Poor service response

"You have to be in the worst crisis ever to get any help."

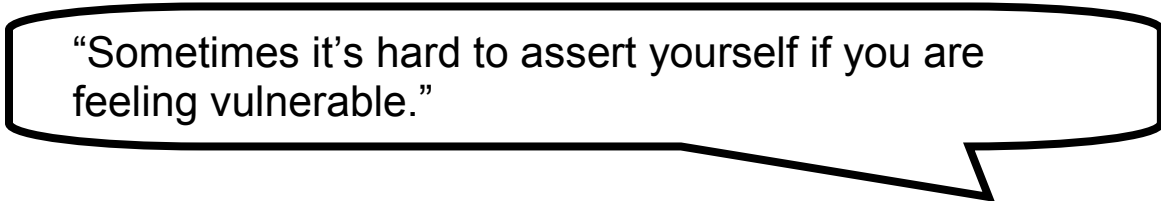Research participant (Group 2)

Many participants felt that their attempts to seek medical help were met by poor service response by GPs and hospitals and sometimes no response at all. One

participant talked about their attempt to commit suicide three times in one day before services took them seriously and provided any assistance. Others felt that they faced constant rejection and judgement when seeking out medical attention. "No matter how much I'm trying to get support, it's not happening." (Group 2) It was argued that successful services were the ones that were part of the wider community and went to people, rather than expecting people to come to them.

Barriers to accessing health services

Many barriers to accessing health services were described, including needing an address to register with a GP and lack of information on where to go for treatment. When asked if participants in the focus groups knew of specialised health services for people experiencing homelessness, the majority said no. Further barriers were discussed once an appointment with a GP or at hospital had been secured and these included not being able to attend appointments on time due to a chaotic schedule and being listened to and treated with respect. Difficulty in maintaining self-care was also cited a as a barrier along with substance abuse which left participants feeling vulnerable and judged whilst attending services.

"Sometimes it's hard to assert yourself if you are feeling vulnerable."

Research participant (Group 2)

3. Non-Discrimination

A human rights-based approach means that all forms of discrimination in the realisation of rights must be prohibited, prevented and eliminated. It also requires the prioritisation of those in the most marginalised situations who face the biggest barriers to realising their rights. (Scottish Human Rights Commission)

<u>Discrimination</u>

Discrimination featured heavily in the conversations surrounding homelessness and the right to health. Discrimination for the participants meant being treated differently, mainly negatively, due to experiencing homelessness. Overwhelmingly, every participant felt that they had been discriminated against in one way or another due to their homelessness status. Female participants, in particular, shared their experiences in regard to facing multiple discrimination due to their gender. Some participants said that they felt extremely vulnerable whilst pregnant and homeless, and believed services were not suited to address pregnancy needs and support women who were pregnant.

A participant did have a positive story in which they described being treated no differently by their GP whilst experiencing homelessness. This was mainly due to the fact that they did not disclose their status to the GP and due to lack of "appearing homeless" the GP was none the wiser. When the participant mentioned their current homelessness status the GP was shocked but continued with the same quality of care and attention to their patient.

It was pointed out by participants and a service provider that discrimination did not occur as often with a GP that the patient was already registered with. Seeking continued support from a current GP was less troublesome than re-registering. Registering with a new GP amongst the turmoil of being homeless and potentially not having a permanent postcode often proved problematic.

Stigma

All participants in the focus groups agreed that experiencing homelessness was highly stigmatised and it was a recurring theme throughout all groups. The stigma the participants discussed ranged from individual stigma to societal and cultural stigmas. "There's stigma. You're brought up that way" one participant (Group 1) explained. According to one participant, stigmatising homeless people is learned at a very early age and thus homelessness is viewed as undesirable and homeless people as people who have done something bad, wrong or had chosen to be homeless. One female participant believed that there were more services and more support available to men who are homeless than women and that there is more stigma surrounding homeless women.

On a few occasions, participants wanted to discuss their negative representation in the media. It was felt that the stigma of homelessness and poor treatment of homeless people was due to media representing the homeless as benefit scroungers and to have chosen their lifestyle. Additionally, participants felt that the media represented those experiencing homelessness as a collective of substance abusers, instead of individuals who were undergoing struggles. There was a consensus that the picture the media had painted of homelessness was a very negative yet persistent one that shaped attitudes towards and treatment of people experiencing homelessness. One participant (Group 2) commented that, "propaganda is a lethal weapon" when describing their experience with how they felt they were viewed and stigmatised without people knowing them or understanding their circumstances.

Some participants discussed how being homeless is not treated as a situation or a crisis in someone's life, but as a characteristic or a value of the person. One participant said that this might allow others to look away more easily because it must have been the individual who caused their own homelessness instead of something that could happen to anybody. One participant (Group 1) strikingly

stated, "empathy and sympathy are two different things" and many participants agreed that both were in short supply when it came to assisting persons experiencing homelessness. Many felt that the human connection is lost or forgotten because of the amount of stigma surrounding homelessness.

Judgement

> "As soon as you say 'homeless' - that's it."
>
> Research participant (Group 1)

Along with facing stigma from society, almost all participants felt that they are negatively judged for their status. "You can tell straightaway if someone is judging you." One participant (Group 1) shared their experience of phoning their local general practitioner's surgery for an appointment and feeling that the receptionist treated them differently, merely by the way that their voice sounded, "they know immediately that you are homeless just by the way that we speak." Many participants felt that the judgment they faced was grounded in negative assumptions about homeless people, mainly in regard to substance abuse. A few participants commented that even after securing accommodation they were still treated negatively and were judged based on past experiences with homelessness.
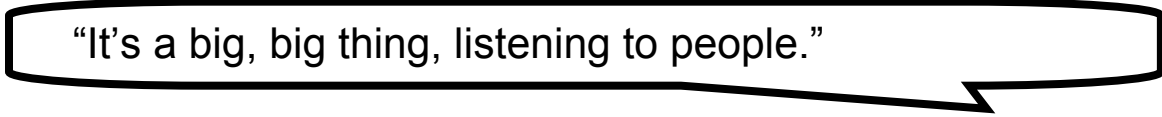
According to most participants, being judged leads directly to feelings of self-blame and guilt. One participant commented on his background from an upper class family and that their own family felt that their homelessness was self-inflicted. Some participants expressed that they felt as if they were "on trial" at all times. Many participants said they felt discriminated against because of their addiction issues and their status. People in one focus group expressed that being homeless means assumptions are made automatically and society assumes that you are an alcoholic and/or a junkie.

The concept of being judged gave rise to several other themes, which are closely related and at times a direct result of being judged and discriminated against. These themes include lack of respect, not being treated with dignity, being blamed for personal circumstance as well as not being treated as an individual.

Lack of respect

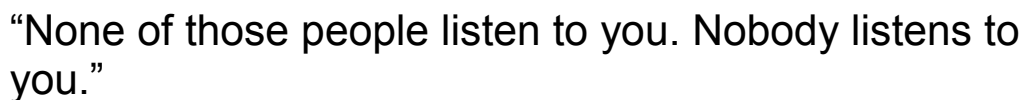Not being respected was a theme that ran across all focus groups. Participants commented that not being respected led in turn to them losing self-respect and directly impacted self-value and confidence. A participant voiced the opinion that respecting people would make a difference rather than spending a lot of money on generic action plans that do not apply to individuals. "You're treated worse than a second class citizen" one participant commented while another stated, "we are not listened to and we are not treated with respect".

Being listened to was a strong on-going theme throughout all focus groups and tied in directly with being respected. Almost all participants felt that they were not listened to by any of the services that they sought out and that this directly impacted their mental and physical health. One participant shared that they engaged in self-harming to cope (with their situation) and that, despite serious self-harming, they were still not listened to by their GP. This led to depression and more aggressive self-harming.

"It's a big, big thing, listening to people."

Research participant (Group 1)

"None of those people listen to you. Nobody listens to you."

Research participant (Group 2)

"It's not just hearing but listening."

Not treated with dignity or as an individual

"They give you drugs. That's not what I am looking for. I'm trying to understand my problem."
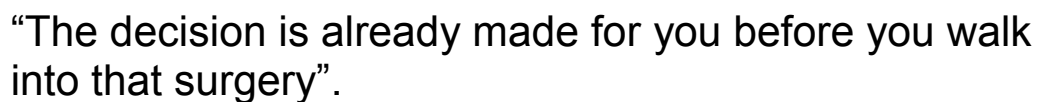
It was made very clear through all the sessions that participants felt, as a direct result of not being listened to, that their opinions and feelings did not matter when seeking medical attention. Moreover, many expressed the feeling that decisions regarding their health and treatment were made for them before they even stepped foot into the surgery. Nearly all participants expressed that they did not feel as if they were being treated as an individual with a unique set of circumstances, but instead were all treated the same. One person commented in their one-to one interview, "It would have been more helpful for me to have been treated like an individual when I was homeless and given the appropriate services instead of what is available". It was claimed that GPs were making generic decisions based on assumptions about the population, instead of treating them as individuals and listening to them.

One participant (Group 1) shared an experience where they sought medical attention at a hospital but were not listened to as to their reasons for the visit. As a result of being ignored the participant grew impatient and raised their voice in order to be taken seriously and explain their medical condition. The participant commented that "once they (medical staff) treated me like a human being, that's when I calmed down".

Due to not being treated with dignity and being overlooked, many participants expressed a lack of trust in the health services. Most participants felt that they were being judged, blamed and grouped with other homeless people, whose experience they did not share. One participant felt as if there were a script that GPs follow in working with people who experience homelessness and that this had led to further trust issues. Many participants felt that their personal circumstance and unique situations were not taken into account and instead they were all given the same treatment in order to get them out the door.

Along with being treated with respect, many participants expressed the feeling of lack of dignity as a person due to their personal circumstance and difficulty in self-maintenance. Many mentioned the small degree of personal hygiene that is attainable when homeless and the embarrassment that they felt in having to seek medical attention whilst in that state. It became apparent that there were compounding factors; stigma, judgement, lack of understanding, and personal wellbeing which led many participants not to seek support from health services and neglect their health.

Discrimination from services / being dismissed

"The decision is already made for you before you walk into that surgery".

Research participant (Group 1)

The majority of participants felt that they had been directly discriminated against when accessing health services. One participant said that they tried calling the GP and the receptionist hung up on them. The above quote was explained as homeless people not being treated as individuals but as a collective with a prescribed course of action, regardless of what their individual circumstance or situation may be when attending a surgery or hospital.

It was remarked that some persons experiencing homelessness can also have a serious distrust of services and other people and thus brace themselves for negative experiences. As participants pointed out, if you were accustomed to being treated badly then a "guard goes up" and the assumption is that you will be treated badly everywhere you go. This could also lead to some persons being hostile and negative from the outset and thus eliciting a negative response from service providers and medical staff.

Taking this into account, there was still an overwhelming sense that some health services and the individuals working within them reflected the stigma and discrimination which homeless persons faced from society and that this was wrong. It was pointed out that a place like a GP's surgery should be a safe place with no judgement.

Forced to disclose personal information to access a service

Many participants expressed difficulties when speaking to receptionists and viewed them as the gatekeepers to the GP or hospital. Participants expressed great discomfort and dislike for being forced to disclose their reasoning for the GP visit when other patients were not expected to do the same. Having to disclose their personal information left many participants feeling more vulnerable and judged.

Not being listened to

As discussed in the discrimination section, not being listened to was a central focus for the majority of participants. Participants had many examples of being disrespected and ignored, most of which directly affected their wellbeing. One participant described how they were given sleeping pills and told to come back a few weeks later. The participant had specifically asked not to be given sleeping pills because they did not want to become addicted. As a result of the sleeping pills they missed their follow-up appointment and felt that due to this they fulfilled
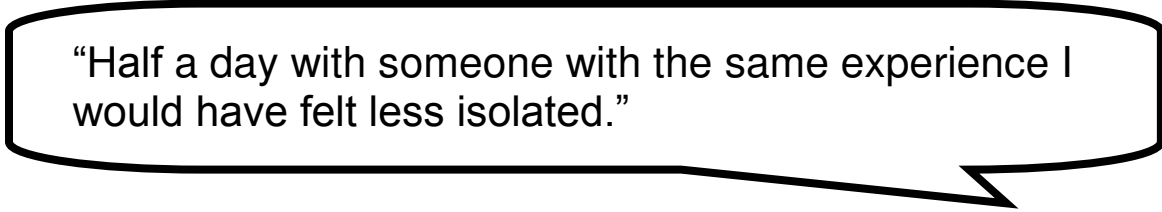
the negative perception people have of homeless persons. Another participant shared how they asked their GP to not prescribe methadone (due to on-going addiction problems) and were prescribed the drug anyway.

4. Empowerment

A human rights-based approach means that individuals and communities should know their rights. It also means that they should be fully supported to participate in the development of policy and practices which affect their lives and to claim rights where necessary. (Scottish Human Rights Commission)

<u>Value of lived experience</u>

In line with the theme of being respected and treated as an individual, many participants stressed the need for health services to understand and address health concerns from the lived experiences of someone who has faced homelessness. Suggestions included having people who are or have experienced homeless train or inform GPs and health staff. It was often discussed that participants felt as if there was a 'one size fits all' approach to people experiencing homelessness and that, due to this, they were not being listened to and proper care was not received. Many said they felt like case studies from a book and not individuals who needed individualised care.
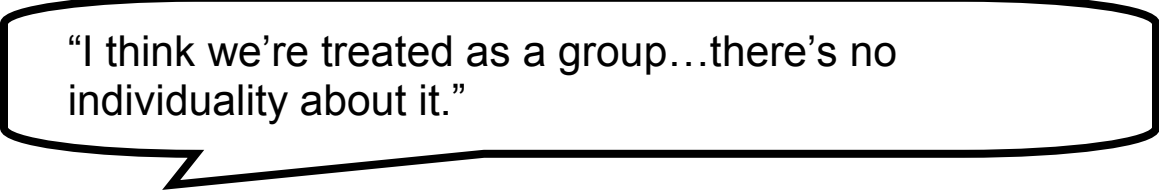
"Half a day with someone with the same experience I would have felt less isolated."

Research participant (Group 2)

One participant explained how they were receiving treatment for alcohol abuse but they were receiving counselling from someone who does not drink. They

questioned how that person could possibly assist and understand their situation if they had never had a drink themselves. Others believed that if practitioners had worked with a person who had experienced homelessness and thus had a greater understanding of the challenges, then this could also result in further 'one size fits all' approach for treatment. What every participant wanted was to be treated with dignity and listened to and not have to fight against assumptions.

Need to treat people as individuals and person centred care
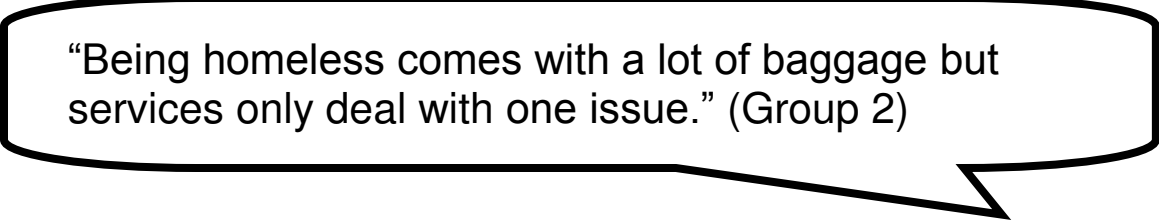
"I think we're treated as a group…there's no individuality about it."

Research participant (Group 3)
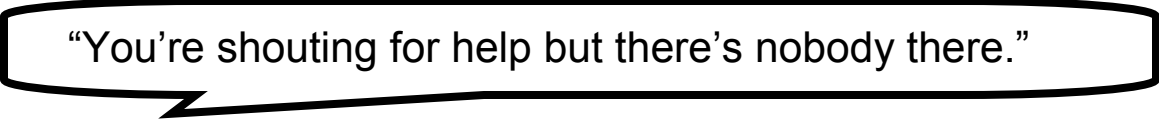
The need to be treated as an individual has already been addressed in greater detail in the discrimination section. Based on negative experiences, many participants felt that a more person centred approach to care was desperately needed. Person centred care is directly related to treating people as individuals in health services. When discussing providing more person centred care, one participant (Group 2) commented, "I'm not unique [in experiencing homelessness]. There's a 1,000 that came before me, there's a 1,000 coming after me." The participant explained that experiencing homelessness is not a new phenomenon nor will it go away any time soon, but by grouping all homeless people together with the same lack of care and understanding, health providers were not addressing the underlying issues of homelessness for each individual. It was compared to putting a plaster on a wound that requires surgery.

Need for better and more specialised services

"Being homeless comes with a lot of baggage but services only deal with one issue." (Group 2)

There were complaints about the difficulty in finding good "one stop shops" which looked after homeless people instead of specialised organisations that provided only one particular type of service. A few homelessness services were recognised as being very helpful and of high quality, while others, especially in regard to the care of women, were believed to underperform. Some participants shared that their substance abuse issues and mental health problems further deteriorated in care and put them more at risk than living on the street and sleeping rough.

"You're shouting for help but there's nobody there."

Research participant (Group 2)

Many participants expressed the feeling that they were not given time to explore all their medical issues in order to attain good health. One participant commented, "as soon as you mention what's wrong with you, you get labelled, 'that's what's wrong with him'". There was a sense that health practitioners did not want to waste time with homeless people or that they too held preconceived notions about what it meant to be homeless. Other participants described attending the chemist and encountering similar issues where stigma kept chemists from treating pain and health conditions because they feared the patients were addicts. They (the chemists) "think you're at it. No experience of you as an individual." (Group 2)

Need for more flexible/24-hour services

Many participants mentioned the need for 24-hour services and seemed to recall this being available at one point in time. The need for more flexible services was based on the recognition that experiencing homelessness is chaotic and unpredictable. One participant shared their experience of living in supported
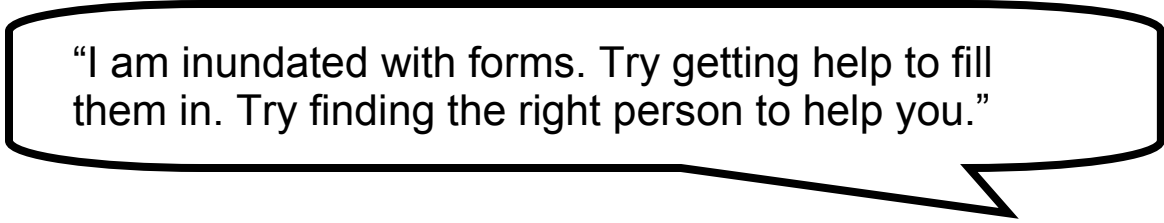
accommodation and described it as "madness". Trying to schedule appointments, arrange for transport and returning to accommodation presented many challenges and it was impossible to visit different services all in one day.

Participants addressed the incorrect assumption that persons experiencing homelessness have nothing to do all day and are therefore available at any time that suits the surgery or hospital. Many pointed out that this could not be further from the truth and, that with daily life shrouded in uncertainty, last minute appointments were more suitable. There was a strong consensus that services need to respond to the chaos of being homeless. Some participants felt that because homelessness is so heavily stigmatised and misunderstood, services have not adopted to better cater to those who are experiencing homelessness.

Difficulty making complaints

Making complaints was regarded as one way to help empower persons experiencing homelessness. However, views of launching complaints and the complaints procedure were varied. Many expressed that they knew how to make a complaint, but thought it was a waste of time. Others felt they were not prepared to make complaints or unable to do so.

The majority of participants believed that the complaints procedure was lengthy and too difficult.

"I am inundated with forms. Try getting help to fill them in. Try finding the right person to help you."

Research participant (Group 2)

Some participants expressed the view that this was done on purpose to dissuade people from filing complaints. The language of complaint forms was described as

difficult, especially if English was not a first language or education levels were low and outside assistance was required to complete the forms. One participant (Group 2) described how they felt "heavily let down by services" throughout their lifetime. They believed that each service protects their own interests and their own people. They tried complaining about staff and treatment during one stay in a psychiatric ward and were told that they would be sedated if the complaint went ahead. Another participant described how they asked for the Care Commission's number and address to launch a complaint against a GP after being prescribed methadone against their will. The participant stated that after being given the contact information, the GP surgery informed them that they no longer qualified as a 'homeless', due to having secured a temporary furnished flat, and asked them to register elsewhere. One further participant in the same group stated, "complaining strikes the fear into me. You're making an enemy of the people who are supposed to be helping me."

Resilience
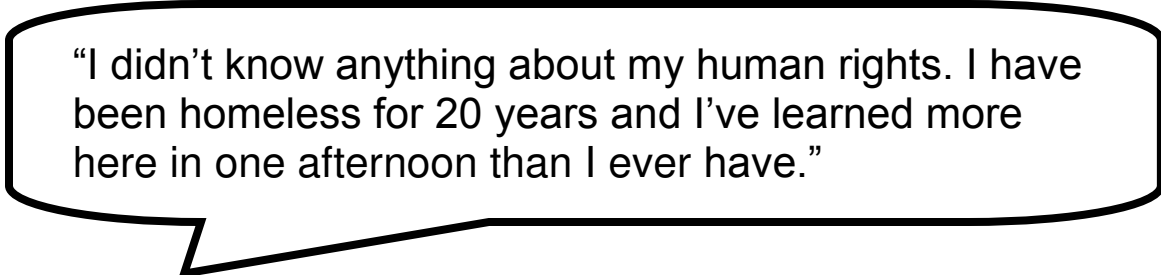
Amongst the negative stories which the participants shared, there were some incredible stories of resilience and personal victories from participants who had experienced homelessness and overcome it. These participants often credited homelessness organisations and individuals who had taken a personal interest in them for their successes. Another, perhaps surprising factor, for overcoming homelessness was the impact that volunteering had on persons experiencing homelessness. Many of the one-to-one interviews revealed the extent to which the participants were active in volunteering for an organisation or charity and the positive impact this had had on their wellbeing and circumstances. For example, asked 'what services do you access to help you feel well?' volunteering received the most mentions (four out of 30), above the community addictions team and the gym (three responses each). Many described the impact of being valued and having something to look forward to as instrumental in their recovery.

Throughout the focus groups the peer researchers met with various participants who were still actively managing their homelessness. Perhaps even more impressive is the fact that many of peer researchers themselves were actively managing or have just recently overcome their homelessness and were now volunteering, researching and being placed in more stable accommodation. The impact homelessness had had on each one of the participants varied greatly, but all participants appeared to be in agreement that being valued and respected as a human being with options and rights was a significant factor in recovery and overcoming homelessness.

6. Legality

A human rights-based approach requires the recognition of rights as legally enforceable entitlements and is linked in to national and international human rights law. (Scottish Human Rights Commission)

Lack of knowledge about rights

"I didn't know anything about my human rights. I have been homeless for 20 years and I've learned more here in one afternoon than I ever have."

Research participant (Group 1)

Potentially the most striking discussions were had around knowledge of human rights. The questions and discussions covered the right to health and the right to housing. Unbeknownst to the majority of the participants, they utilised human rights language and principles throughout most of the discussion, but would not have identified or labelled them as such themselves. For example, one person commented in their one-to-one interview, "everyone should have a bed". Almost

all groups expressed that when hearing or thinking about human rights they did not think of themselves or the United Kingdom, as human rights, in their opinion was something that was needed in developing countries. As one participant (Group 1) stated, "people would think of the third world and war but not of Glasgow".

When asked about their human rights and specifically their right to health, many participants expressed that they did not feel as if they had any or as if the concepts applied to them. Other participants knew they had rights but did not know how to verbalise, defend or claim them. This is demonstrated by one participant (Group 2) who began speaking about rights and then said, "it's my legal right…but…" Still others felt that rights were being withheld and not made accessible to those who needed them most or who would benefit most from accessing rights; "they don't tell the people that matter. If they do then you can't access it."

Despite sharing personal stories of discrimination and human rights violations, the majority of participants did not realise that they were speaking about human rights. For many the idea of human rights was reserved for developing or war ravaged countries and if it applied to the United Kingdom then it was part of complex legal system of which they did not have any understanding. Some participants became aware throughout the sessions that the research questions and discussions were centred around human rights and that their experiences were directly applicable to the human rights discussion. A variety of participants also questioned the effectiveness of human rights, as having 'a right to housing' had not translated into reality for themselves or many of their peers. Those who did express knowledge of human rights believed that the system was too difficult to navigate and, since they had no standing in the community anyway, that trying to claim a human rights violation was futile. Furthermore, participants were eager to identify that they were not the only group who did not know their human rights,

but that this information was withheld from a variety of different communities, "loads of people don't know. Pensioners don't know!"

Poor information on rights and entitlements

There was a real sense from the participants that information was being withheld from homeless people because of the fear that if everyone knew their rights then everyone would want their rights fulfilled and claim their benefits. As one participant stated, "they're withholding information. Is that not a bit iffy?". In some of the participants' views, the justification for this was that keeping people ignorant of what they are entitled to was much easier and less expensive. "You need to ask," one participant (Group 2) stated, "no one tells you nothing." Another participant clarified, "it's in the word itself, entitlement; it's not like you're chasing a debt. You're entitled to it!" This discussion often arose after participants were asked if they knew that there were speciality health homelessness services available to them in Glasgow.

In one session (Group 2), a participant noted that they had not been informed of what they were entitled to in regard to hostel accommodation until they were paired with a solicitor of a Glasgow agency. After sharing their story about how much more respect the solicitor received and what options were thus made available to them, they were shocked by the lack of information about entitlements made available to their community. In response another participant stated, "if you're entitled to it then please let the people know". Outreach to the homeless community and communication with individuals was regarded as weak, if not non-existent. Some Glasgow organisations were praised for their efforts and the support they provided, although, as mentioned previously, it was felt that services could deal with only one issue at a time and that the homeless experience carries "a lot of baggage" which services are not equipped to handle.

Overall, it appeared that the idea of human rights and a right to health was very far removed from many of the participants. As the discussion and various themes

above illustrated, many persons experiencing homelessness felt as if they are already treated as second-class citizens, criminals or even ignored altogether. It is therefore unsurprising that many did not identify with human rights and the potential benefits of a human rights-based approach to health, as many had not experienced the very basic support required whilst being homeless. Despite highlighting human rights issues such as severe discrimination, lack of participation, and difficulties in identifying whom to hold to account for violations; many participants did not view these issues as human rights issues, nor did they believe that there was a system which challenged all these issues on their behalf. The idea that there is a framework that would work for them, instead of against them, is one that felt very far removed.

Summary

Overwhelmingly, the experiences that the research participants shared in regard to their homelessness status and health and human rights were negative. Every single one of the participants had experienced on-going discrimination due to being homeless and some, particularly females, had experienced multiple discrimination when seeking help. One female participant commented on domestic abuse being the cause of her homelessness. She revealed that being homeless due to domestic abuse meant she faced multiple discrimination: victim-blaming in regard to domestic abuse alongside being female and homeless. The participant felt that the discrimination was only compounded when she fell pregnant.

The idea that human rights applied and that the participants had the right to health and housing was far removed from their realities. All participants agreed that they should be treated as individuals and thus with dignity and respect but their lived experiences did not reflect this treatment. The extent of discrimination revealed through the focus groups and one-to-one interviews was shocking. It appeared as if people experiencing homelessness were completely marginalised

from society and encountered discrimination at every level when seeking assistance (individual, community, professional). Moreover, many participants felt that there was not much that could be done about this because stigma toward the homeless was deeply ingrained in society and culture.

Participants throughout the sessions made some very interesting observations about what it meant to be "healthy" and what they required to be healthy. Just as the right to health states, participants acknowledged and spoke about the right to health not merely as the absence of disease or illness but as an all-encompassing state of being, including physical, mental and emotional health. The research participants were quick to make the connection between being marginalised and the impact this had on overall health and wellbeing. Furthermore, participants readily explained the importance of housing (safety, security) and its connection to mental health and physical wellbeing. Many highlighted that even temporary accommodation did not allow for them to regain their health due to uncertainty about future housing and not feeling safe. Healthy eating to support the body and mind was also mentioned, but most participants described the potential of receiving high quality food as extremely limited, if not impossible.

The very few positive stories which were shared by participants were results of an organisation or an individual taking personal interest in their circumstance and supporting them. Encouragingly, many participants felt quite positive about the help they had received from a variety of homelessness organisations in Glasgow. However, as stated in the findings, almost all participants felt that the organisations were not able to deal with more than one issue at a time and this left homeless people seeking assistance from numerous organisations, which was not desirable nor realistic given the homeless lifestyle. The one-to-one interviews also revealed very positive involvement from participants in volunteer and outreach work. Many cited volunteering and community engagement as a

positive motivator and a way in which they managed their status in order to feel valuable and as a part of society.

The most striking findings from this group was the disconnect between their experience and human rights. Almost all of the participants discussed key concepts (participation, non-discrimination, accountability), but were unaware that these represented human rights principles and were significant in bringing about change for themselves and their communities. Most felt that human rights were reserved for developing countries, far removed from Glasgow, and not concepts that applied to their daily lives. Even once the concepts of human rights were explained, the participants pointed out that in theory human rights were on their side, but that the reality was far removed from that.

Asked if they had heard anything unexpected in the groups and interviews, the GHN peer researchers said that they were surprised to hear that some people had found it so hard to access a doctor. What did resonate with their experience was the stigma that people had experienced. Even when people were housed in temporary accommodation they said that other people knew the properties – you can "spot the curtains". They had witnessed the frustration that people felt at not being treated as individuals; "labels must be removed" said one. They had heard how there were lots of missed opportunities to intervene and how often people did not get help until they were "at death's door". They also thought that people were reluctant to complain because they did not believe it would achieve anything and did not know what to do if they were discriminated against.

Female refugees and asylum seekers

Introduction

The peer researchers from the Mental Health Foundation conducted focus groups with 49 participants from a variety of refugee and asylum-seeking support

services throughout Glasgow. This section provides an overview of the key themes that became apparent throughout the data collection process, an explanation of the themes as well as examples and quotes from the participants.

The section begins with an overview of the overall impact the asylum process and having refugee status has on health. This is followed by the themes discovered according to the human right- based approach (PANEL) structure. We acknowledge that several themes fit under a variety of PANEL headings, but for easy readability we have presented the themes under the PANEL heading which was believed to be most relevant to the research participants. This is not to establish a hierarchy among the PANEL headings but simply to represent more accurately the way in which participants spoke about the different themes and how they themselves interpreted and categorised them. To assure consistency in human rights research, the PANEL definitions are the same as presented by the Scottish Human Rights Commission and as can be found in Scotland's National Action Plan for Human Rights.

Impact of asylum process and refugee status on health

"The stress I am getting from Home Office is too much," one participant (Group 1) explained as she retells the story of being prescribed medication for on-going symptoms of stress and trauma. According to the participant, the medication prescribed is not working because it is not addressing the underlying causes of the stress and anxiety, although due to negative experiences in the past, she does not feel as if she has the power to ask her GP for other medication or alternative medicine.

Throughout all the focus groups it was evident that the asylum-seeking process and being a refugee in Scotland was a very difficult endeavour with far reaching physical, emotional and mental health consequences. The research participants in these groups had a very clear understanding of how health is not merely the

absence of disease, but a day to day endeavour which is affected by your surroundings, your nutrition, your mental wellbeing and even the feeling of belonging to a community. However, participants felt overall that this was not recognised by GPs and hospitals and believed their mental and emotional state was not addressed properly.

What provided a great source of distress was the worry almost all participants felt for their children. It was not uncommon for the women to have sacrificed their health and personal wellbeing for that of their children. The discrimination the women themselves faced was only compounded by the fear and worry of the discrimination their children might face. As one participant (Group 2) stated, "I stay strong for my children. They cannot see me like this (weak and afraid)".

Mental health impact

As with the homeless participants, mental health was a recurring theme throughout all focus groups. The women spoke about their journeys to the UK and their resettlement and how feeling low and depressed were commonplace. Many of the participants felt that health practitioners did not have a thorough understanding of the mental health consequences asylum-seeking has on an individual. Trauma, fear, distress and worry were all part of some women's daily lives and some GPs, they felt, were only interested in treating the physical symptoms which manifested as a result. In addition to the asylum-seeking and resettlement process, many participants spoke about the discrimination and racism they faced in Scotland which added additional distress and worry to their lives and to that of their children. According to many of the research participants, being a refugee is highly stigmatised. Despite having spent many years in the UK, they were never regarded as 'British' or as citizen altogether, which left them feeling out of place and added to further imbalances in their mental health and wellbeing.

The right to health according to participants

As outlined in the methods section of this report, participants were asked at the beginning of the focus groups to engage with the question, 'what does the right to health mean to you?' Each participant had a selection of picture cards to choose from when deciding what they thought of when they heard the words 'right to health' and 'human rights'. Below is a random sample of picture cards which were chosen and the description of the card as stated by the participant who selected it:

"Everyone is the same and everyone has the same rights, regardless of their ethnicity. "No different, black or white, woman or man; same rights."

Research participant (Group 2)

The research participant (Group 3) explained that human rights is about listening to people. Not just hearing a person but listening is the key to human rights and health.

"Human rights are attached to all of us. Sometimes we are told we have rights but they are not fulfilled. The participant felt that human rights are broken most of the time and not protected. The government and human rights law say that rights are protected, they say "we will do it but then they don't".

Research participant (Group 3)

1. 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. (Scottish Human Rights Commission)

The participants in the different focus groups had divided opinions on their ability to participate in their right to health. Experiences ranged from very positive interactions and autonomy to acts of direct discrimination and racism. Many participants felt that they were listened to by their GP and they felt confident and comfortable in seeking medical attention from GPs and hospitals. "I like my GP. It is the person. It is different from person to person", one participant (Group 2) stated as she explained that the ability to participate in one's health did not

depend on the structure of the NHS, but on who your GP was and their willingness to be a good service provider and person.

Other participants agreed with the idea that it depends on the type of person that the GP is, but had encountered too many negative situations in order to be willing to engage with the GP any further. "If I am sick, I call my friend", one participant (Group 4) stated. Another participant (Group 3) shared her story of suggesting an alternative medication to the one which was prescribed by her GP because she knew she would experience negative side effects; the GP allegedly responded with "how do you know this is going to help you?". The participant interpreted this as a reminder that the GP was the professional and not her. Another participant (Group 4) found herself unable to walk and take public transport to her Home Office appointment in Liverpool. The participant spoke to her GP and relied on the GP to confirm her inability to take public transport to the Home Office and thus postpone the date of the interview. The GP declared her medically fit and now this participant no longer seeks professional health services, "I feel let down. I don't trust," she said.

2. 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 in order to secure human rights.
(Scottish Human Rights Commission)

Experiences with services

The experiences the participants had with services varied greatly. However, unlike the homeless participants, many women did have positive stories of their experiences with the right to health and accessing health services in Glasgow.

Good experiences included the information pack that all asylum seekers are provided with upon entry into the UK. Many of the participants were very positive about the information provided, and despite limited knowledge of English or their surroundings, felt that they were able to access a GP service quickly and without difficulties. Almost all participants cited access to, and availability of, health services as very good, although quality and acceptability were rated less positively. It appears almost as if structurally everything is in place for quality health services, although on an individual level the services were regarded poorly.

Among the critiques of health services, lack of continuity of care and racism within services were cited as overarching concerns. Some participants shared their experiences of not being able to be seen by the same GP, despite their requests. In addition, having to change GPs once postcodes changed also created discontinuity of care and frustration with many participants. Many claimed that building trust and a relationship with a GP was difficult enough, but being expected to do that numerous times was distressing.

Racism within services was also cited as a serious concern. Some participants felt unwelcome and rejected from some GP surgeries because of the colour of their skin or religious beliefs if they were wearing a headscarf. They claimed that interaction with them varied from other people who used services and complaining about this would result in disbelief and denial from other staff. One woman's experience (Group 4) left her quite shaken and she states, "I see I have a problem but I refuse to go to the GP".
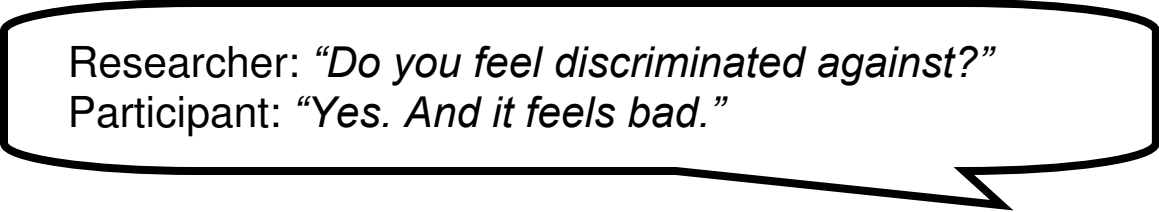
As with participation mentioned above, many women felt that they were not being listened to when seeking medical assistance. This could either be due to language barriers, not asserting themselves due to cultural differences or the GP not respecting their cultural beliefs and remedies. Some participants did not

share this experience and stated that their GPs listened, interacted and took on board their concerns. Furthermore, some participants stated that if they mentioned a preference for herbal remedies (as common in their country of origin) that this was taken into account by the GP. Thus experiences varied on a case by case basis and no clear majority had good or bad experiences.

One phenomenon that every participant seemed to relate to was the underestimation that the impact of seeking asylum has on a person's health. Some women shared that their GPs were more concerned with present conditions than on-going trauma that was caused by fleeing / leaving their home countries and resettling. The stress and trauma caused by seeking asylum and being a refugee, in what was perceived to be a refugee-hostile country, was not often addressed, but seemed to be an on-going issue for many women.

3. Non-discrimination

A human rights-based approach means that all forms of discrimination in the realisation of rights must be prohibited, prevented and eliminated. It also requires the prioritisation of those in the most marginalised situations who face the biggest barriers to realising their rights. (Scottish Human Rights Commission)

Researcher: *"Do you feel discriminated against?"*
Participant: *"Yes. And it feels bad."*

Stigma

Regardless of whether their experiences with the right to health in the UK had been positive or negative, all research participants agreed that there was a distinct stigma attached to being a refugee or asylum seeker in the UK. Even participants who reported overwhelmingly positive experiences since coming to

the UK, felt as though they were only seen as a "refugee" or as "an asylum seeker". One participant, who has since her arrival secured indefinite leave to remain and whose children are British citizens, expressed feeling as if she is being treated as a non-British citizen and thus second class and undeserving.

Many participants described how they were made to feel unwelcome and unwanted, as if they were in the UK to steal benefits, instead of being vulnerable people from war-ravaged countries seeking assistance. Some participants vocalised how difficult it was to be faced with such blame after fleeing distressing situations and trying to provide safety for their families. The blame caused some participants particular distress and they said it affected their mental health greatly.

<u>Racism and Islamophobia</u>

In line with being blamed for their status and being treated as second class citizens, almost all participants felts as if they had experienced racism in the UK and more specifically by service providers. The racism took many forms from direct conflict to subtle looks and refusal of treatment. As mentioned in the participation section, some felt as though their cultures and methods of treatment were ignored or belittled. These experiences left some women no longer seeking treatment when ill, solely going to A&E for treatment or only attending a GP surgery as a last resort. Other participants stated they did not let racism stop them in seeking treatment, however, they did feel as if there was a lack of assistance with confronting the racism and maltreatment.

Islamophobia was cited numerous times as a serious issue with the research participants. Interestingly, the women did not necessarily speak about it affecting them negatively as much as it did their children and the participants' health and wellbeing was linked directly to that of their children. One participant (Group 2) tried to explain the negative treatment her daughter received for being Muslim at

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her school but all she was able to say was, "my daughter wears the scarf". Other participants nodded in agreement, demonstrating that the mere mention of a headscarf was enough to evoke emotion and distress due to the negative perceptions in the UK. Another participant (Group 2) shared that the headscarf obviously gave away a person's religious beliefs and concluded, "now they know your religion, they don't care". The range of experiences with Islamophobia varied for the participants. Some felt it was present at all times and they faced discrimination because of it. Others felt that it did not impact their daily lives but they worried for their children and thus it impacted their own health and wellbeing.

Language as a barrier

Despite the command of English being exceptional in almost all focus groups, the research participants expressed concern in regard to language acting as a barrier when seeking assistance. Interpreters were a topic for much discussion with varied opinions on their effectiveness and quality. Some women were very grateful for their interpreter as their command of English was rather poor but did not feel comfortable discussing health concerns with another person in addition to the GP, especially if the person was linked to their community in some way or another. Others had no issues with being provided with interpreters or the roles they played. Furthermore, some participants were not at all pleased with the provision of interpreters, especially when they told reception that none was needed. Some participants questioned the quality of the interpreter as they had just enough English to understand the GP and realised what the interpreter was saying was incorrect or not in line with the GP's words. There were also participants who felt that their access to interpreters had been denied and that this was a further act of discrimination due to their status.

In addition to language presenting a barrier when seeking assistance, participants also mentioned language as a barrier when trying to file a complaint.

Feeling insecure about not being able to communicate properly was a significant barrier in challenging GPs, receptionists, and hospital staff.

4. Empowerment

A human rights-based approach means that individuals and communities should know their rights. It also means that they should be fully supported to participate in the development of policy and practices which affect their lives and to claim rights where necessary. (Scottish Human Rights Commission)

<u>Good knowledge of rights and access to information</u>

The various research participants had mixed opinions on knowledge of human rights and where to access information. There were participants who felt very positively toward the information they had been provided with upon entering the country. They knew where to go to access information and believed all information provided was easily understood and sufficient and they knew how to complain. Information regarding how and where to access a GP was all provided for and almost all participants agreed that locating their GP upon arrival had not been an issue. Overall, the response toward information provided on arrival was very positive and not many felt that it could be improved upon.

An interesting discussion took place in one group where older women felt that the newer generations of asylum-seekers had more access to information and things had been made easier through the availability of the Internet. However, younger/ recent asylum seekers claimed that older generations did not face the severe backlash toward refugees and asylum-seekers which current women face. No agreement was reached on which generation had the better transition to Scotland.

Many participants compared their current status with respect to human rights to the rights they had in their country of origin. Unsurprisingly, many found that their lives had improved whilst living the UK and that the topic of human rights was more present in the national dialogue than in their home countries. Whether or not this dialogue translated into rights for everyone on the ground was a different matter. Quite a few participants regarded quality of information as quite high and easy to access, if not, they knew where to go to get clarifications and further information. The information pack provided upon entering the country was overwhelmingly seen as a success. The majority of participants felt that they had been provided with sufficient information upon entering the country.

Lack of knowledge about rights

Although most participants knew about the concept of human rights, there was a degree of uncertainty about human rights in the UK. As mentioned previously, many participants fled conflict countries because they knew their rights were not being fulfilled in their country of origin. Upon coming to the UK it appears that there is some confusion around what rights the participants are entitled to now that they have refugee or asylum-seeking status. It appeared almost as if the label of "refugee" did still not guarantee or warrant them full citizenship and human rights.

Some participants knew exactly what their rights were, and what they were entitled to as a refugee or asylum seeker, and believed strongly that the UK was not fulfilling its obligations under international law. Others felt that their rights were being actively denied due to their new status in the UK. One participant found herself homeless and quite vulnerable upon entering the UK and believed that the authorities were purposely not coming to her aid.

A lack of control over one's life during the asylum process was cited as one of the main reasons why knowledge of rights was so difficult to obtain. Not being

able to work, racism and lack of outreach were all cited as causes for confusion about what rights pertained to whom and at what part of the asylum process. Furthermore, not knowing who to turn to for advice and assistance on claiming rights was also a barrier.

Difficulty making complaints

Not knowing how to complain when experiencing discrimination or insufficient services was a common theme among the participants. "I don't think we know the right thing to do," stated one participant (Group 3). Others who knew how to complain felt that their complaints were not taken seriously or not acted upon, as one participant (Group 3) explained, "you speak out and nothing's been done. It makes you worse! You just want to run away". One participant (Group 4) told her story of direct discrimination at the hospital and despite knowing how to make a complaint against the staff in question, she confessed, "I was too shocked to do anything!".

Being afraid to complain in case it affected asylum seeking or refugee status was commonly cited as one of the main reasons for not issuing a complaint. Some participants felt that a complaint could draw unwanted attention and directly affect their status if they were seen to be ungrateful for their lives in the UK.

The right to health

The women in all groups recognised health as not just the absence of disease or illness. Being healthy and having health was described as "everything" by many of the participants. As one participant (Group 1) stated, "if you do not have your health, you have nothing." Food, shelter and lifestyle were often cited as contributing factors to health and they were issues which most of the participants had experienced a lack of in some degree or another. For the participants who were mothers, caring for their children and providing them with proper nutrition was not only essential to their children but to their own wellbeing as well. Many

who were mothers expressed serious concern in regard to their children's wellbeing and this indirectly affected their health as well.

Nearly all participants were members of one or numerous refugee and asylum seeking organisations for women and through this network they have been able to seek advice, guidance, and support from others in their community and from women either native to or settled in the UK. Many participants said their memberships kept them healthy as it gave them a place to go and a purpose. Having a purpose in life and the impact this has on health was also discussed frequently. Not being able to work whilst seeking asylum and then being discriminated against, as a refugee, was an experience that left many of the participants feeling hopeless and distressed.

An interesting point was raised by a few participants in regard to their health in their home country in comparison to the UK. Some participants felt that their overall health and wellbeing had been significantly better in their country of origin than it was in the UK. Reasons cited for this varied from more opportunities to go outdoors due to the weather, closer proximity to family and relatives and better nutrition available in fresh fruits and vegetables. Many participants came from cultures in which life was spent outdoors and felt that being inside due to the British weather was affecting their quality of life and health negatively.

5. Legality

A human rights-based approach requires the recognition of rights as legally enforceable entitlements and is linked in to national and international human rights law. (Scottish Human Rights Commission)

Human rights in country of origin compared to the UK

Interestingly, many participants believed that their knowledge of human rights had increased since living in the UK, although fewer of those rights were fulfilled.

Many of the participants came from on-going conflict and developing countries. Their incentive was to leave their country of origin in order to secure a better life for themselves and their families. Most participants had a very good understanding of their human rights and recognised that these rights were being violated in their home countries, which is what led them to the UK. However, upon living in the UK, many participants felt that although they were safer, their rights were still not being fulfilled. As one participant (Group 3) stated, "everyone talks about, you have a right… You have a right to this in the UK, you have a right to that…where is it?!"

Refugees and asylum seekers not a priority in the UK

The majority of participants felt that they were not a priority or treated as a vulnerable community in need of special assistance. As mentioned above, some felt as though they were personally being blamed for being a refugee or asylum seeker and thus not vulnerable at all but instead as people who were asking for hand-outs. Although the group had mixed experiences in regard to the right to health in the UK, almost all seemed to agree that their status did affect them in a negative way and that the perceptions toward asylum seekers and refugees were not at all that they were entitled to special care or priority.

Summary

The refugee and asylum-seeking participants had varied experiences of the right to health and human rights in the UK. It was evident from the focus groups that nearly all participants had a good understanding of what human rights were and the right to health as it applied to their day-to-day lives. The participants fully understood the impact factors such as nutrition, community, and emotional wellbeing had on their health and where possible tried to optimise all of these to assure greater health and wellbeing for their families and themselves.

Despite a good understanding of the role and importance of human rights, the participants did not seem to believe that human rights applied to them in the UK due to their ever-changing legal status and lack of citizenship. Furthermore, if participants knew they were being discriminated against then many were uncertain on how to complain and worried that a complaint would affect their status in the UK.

What arose from the focus groups was a distinct sense that there was not a culture of discrimination in health services but that individuals did discriminate. Many women shared positive stories about their visits to GPs and hospitals and believed that with the 'right GP' there were no issues. Whilst others felt discriminated against and undermined due to their religious beliefs or colour of their skin. What is troubling is that participants believed there was such a thing as 'right GP' or a 'good GP' and that the practice of non-discrimination was not consistent across the board of health practitioners.

A serious concern was the rise and role of Islamophobia in the experiences of the research participants. The majority of women who took part in the focus groups were Muslim and nearly all of them felt discriminated against based on their religion. None of the women spoke about cultural sensitivity being breached or inappropriate care, although many felt that they were treated badly or with less interest due to their religion. The distress caused by being discriminated against due to religion did not end with the participants themselves but also was a great cause of concern for the treatment and wellbeing of their children. Often it appeared that the treatment of the children was more significant than any discrimination the participants themselves had endured.

A real positive for the participants was the various women's organisations, which they belonged to, specifically for female refugees and asylum-seekers. The participants were very thankful for a safe space with other women from their

communities and the opportunity to share their experiences with others who understood and could relate. The organisations provide a real support network for the participants and were believed to play a vital role in their integration into Scottish life whilst maintaining a connection to their cultures and communities.

Lastly, the participants all felt very strongly about the information they had received upon arrival in Scotland. Access and availability to health services was made very clear and only few women struggled to make sense of the health services upon arrival. Although different generations believed that the rhetoric around asylum-seekers had changed drastically in the past 20 years, all believed that they were provided with the necessary and good quality information needed to resettle.

The two peer researchers who volunteered with the Mental Health Foundation discussed their impressions of the groups they had facilitated. Their impression was that about half of the participants were aware of their human rights and half were not. Both were struck by the depth and quality of comments and feelings offered in response to the picture cards. One had noted that several participants had used these to express the view that despite different nationalities "we are one". The other commented on the surprising level of detail in some responses. They felt that communication was a key theme and that many women asylum seekers and refugees would not be likely to seek help, talk about her problems or speak out. The most important thing was for the women to be treated as people and not labelled with a category such as 'asylum seeker', a term the peer researchers themselves rejected as an identity.

The research process

This study was intended as a first attempt to take a participatory approach to exploring the meaning of the right to health from the perspectives of people experiencing health inequalities. As a preliminary study, there were practical

limitations on the number of groups that could be included in the research. People experiencing homelessness and women refugees and asylum seekers were among the priorities we identified, but the final choice was also partly pragmatic and we recognise that there are many more groups whose experiences would be valuable and who may bring different perspectives. Similarly, as the timescales for the research were short for a participatory process, the number of focus groups and interviews that could be conducted was constrained and the range of participant experiences included depended on the contacts and networks of the organisations involved. Nonetheless the target number of groups and participants was achieved in both parts of the study, representing a considerable effort on the part of the peer researchers and their supporters. The women refugees and asylum seekers included both those recently arrived and women who had been in the system for many years, as well as women who no had citizenship. Both groups benefitted from hearing the reflections of people who had had the experiences in question and 'come out the other side' and the peer researchers contributed their experiences to the groups, where relevant.

The research was collaborative in nature and this brought considerable benefits and also challenges. The research benefitted from a range of skills and knowledge – of human rights, participatory research, research management, volunteer support etc., but also relied on people fitting the demands of the study around other priorities which could create a sense of pressure at times and meant that the conduct of the research depending to a large extent on the good will and commitment of those involved. The contribution of the staff from the partner organisations that supported the peer researchers – Glasgow Homelessness Network and the Mental Health Foundation Scotland - was of critical importance to the success of the research. Without them the peer researchers would not have been identified or such easy access gained to research participants. They played a considerable role in making the research

possible by arranging meetings with the peer researchers and participating groups, organising expenses and travel. However their support to the peer researchers was more than practical. It was their involvement that encouraged the engagement of the peer researchers and they helped to shape the research sessions and translate the research process into a meaningful experience for them, sustaining their engagement in a variety of ways. As one of the GHN peer researchers commented: at first he thought it wasn't for him and would have walked away, but the staff member at GHN helped him see why he should be involved. In the course of the study strong working relationships developed between those involved across the organisations and roles became flexible. Thus the process was co-productive, involving the sharing of skills and knowledge (Scottish Co-production Network, undated).

The commitment of the peer researchers was a highly significant feature of the study. They explained the reasons that they chose to take part when they introduced themselves to research participants. For example:

"Why I am here today

I am here today as I passionately believe that everyone irrespective of your journey or current circumstance in life, should always be included, supported and given every chance to be part of your community and society. Everyone has something to offer, share or untapped potential waiting to be opened and no plight should ever be a continuous wall to shut you out and exclude you from *hope!"* (Peer researcher, Glasgow Homelessness Network)

For all of them the main motivation was to make a difference to the lives of other people and what appealed to them about the research was the commitment that the findings would be taken to the Scottish Parliament and Government. In other words it was the 'action' part of 'action research' that was the main incentive.

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The peer researchers were aware not only of their own life experiences, but also of those of others through their involvement in groups and as volunteers.

There were challenges faced by the peer researchers in the course of the study. The GHN group was deeply affected by the death of one of its members. Though this inevitably interrupted the preparations of the research for a short time, if anything the group became stronger in its commitment to complete the research. Of the original MHF group who came to the training, only two were able to continue as peer researchers which placed a heavy demand on them and meant that there was less capacity available for full engagement with the study.

One of the aims of the study was to learn about the feasibility of the process. Reflection on emergent learnings took place in the interagency research steering group, in the preparation and debrief sessions with the researchers and in preparing for dissemination events. The principal reflection was how hard it was to translate the 'right to health' into a meaningful and grounded concept. A definition of human rights and an explanation of the PANEL principles was provided to the peer researchers and participants and used as an organising framework for the interview schedules and analysis and presentation of research themes. Nonetheless it remained an abstract and elusive entity. The peer researchers were not fully confident of their knowledge of human rights and its application to health and all were agreed that both in devising the schedules and in conducting the groups and individual interviews it was easier to focus on barriers to access to services than on health and rights.

The plans for the research also underestimated the time and capacity required for a participatory process. Only one day's training with the peer researchers was factored into the planning. In the event a series of preparation sessions was required to engage people in the development of the research and to prepare for the sessions. This was achieved nonetheless through the goodwill of those

involved. However this did lead to slippage in the research timetable. The preparation phase lasted from June to November 2015 and the data collection had be completed quickly between December 2015 and January 2016. Participation was greater in the phases of interview development and data collection and was less in the analysis and write up phase; there was no involvement of the peer researchers in the ethics application process which was handled by the university.

It was a considerable achievement that the number of expected sessions and participants was achieved. Given the life circumstances of the people being asked to take part in the groups there were inevitably challenges in achieving attendance at the sessions. It proved hard to cover all the questions in the time available, sometimes people had commitments that meant they had to leave the group before the end and it could be a challenge to keep the groups on track. In the asylum seeker and refugee groups, interpreters were present to assist participation and this created a further layer of complexity. One way that participation was achieved for these groups was to build the research session into or linked to a regular group meeting. An early piece of learning for the MHF arm of the study was that it was necessary to specify a limit to the number of participants and a dedicated time and space, as a first attempt at a focus group was compromised by a large group, only some of whom wanted to consent to take part and a late start, resulting in only one of the questions being fully covered.

A further limitation was that in a one-off session with each group it was not possible to follow up all the comments in depth. However participants engaged very willingly in the subject matter and were interested in the subject of rights. Some spoke more than others, but rich insights were provided in response to the picture cards and experiences and views were openly shared, encouraged by the involvement of the peer researchers.

The peer researchers got involved in order to make a difference. They also felt that they had gained benefits from the process. Reflecting on their experience of the research, the GHN group commented that it had been good to be involved right from the start. They liked the way it had been possible for people to take different roles, one as a welcomer, two are facilitators, another as a note taker. Moreover roles developed as people's confidence grew and a person who had started by being the welcomer later conducted one-to-one interviews. One learning from the work for the whole research team was how keen the peer researchers were to improve their skills and the importance of feeding back to them how they were doing. By hearing from the participants one peer researcher said that he had learned a lot that he could use to help others in his work as a volunteer. Another had, as a result of the research experience, gained work in research in another organisation.

The theme of learning was echoed by another peer researcher on one of his debrief forms. He wrote; "I really enjoyed my role [facilitating]; it has opened my eyes up more than I thought. It is amazing that society as a general isn't kind to those with addictions and detrimental poor health and homelessness. They are smart, knowledgeable and very resilient, the landscape just doesn't give them equal rights". The peer researchers took pride in creating a safe, open environment and respected the participants or what they had experienced and for their openness. In turn, it seemed that the role of the peer researchers was critical to a creating a trustful environment in which participants felt they would be heard. The peer researchers felt that the research participants would not have opened up so readily or in such depth if the discussions had not been led by someone with similar experiences. One of the peer researchers for the refugee and asylum seeker women's groups noticed that the women addressed their comments to her rather than to the other researcher who was present. The MHF peer researchers, like their GHN counterparts, heard the experiences from

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participants with great respect. One described the team work with the researchers from other organisations and also felt she had gained new skills. She was moved to meet the GHN researchers and hear of their life experiences and could see their achievement.

Other outcomes for the peer researchers included increased confidence and a sense of achievement. One person had really enjoyed his first one-to-one interviews, for once being the interviewer, rather than the person being interviewed, and able to listen with the respect he wished that he had been afforded. All felt that they had gained in confidence, building on the empowerment they had experienced through volunteering with Navigate and marking a further stage in their recovering and in being able to give something back to others. Increasing confidence is apparent on the peer researcher's debrief forms, for example: "My increased confidence made me more confident in my role. I felt I was able to control and facilitate the discussion and make sure the objective of the research was met." For one peer researcher, the work had been an opportunity to discover that he could see now something through to the end. The group commented that they only really appreciated what they had achieved when they came to reflect on it together. They came to understand that they had created new capacity in the organisation as well as new capabilities in themselves.

Conclusions and recommendations

Conclusions

This report has highlighted a wide range of important factors on what the right to health means for marginalised groups in Scotland. These issues fit well within the PANEL framework and highlight a number of common issues experienced by both sets of participants which should be a priority for services to address. Making complaints was perceived by both groups as something that was complex and undesirable. Both groups felt that the amount of paperwork involved in making a complaint was excessive and the process was complicated. The women's groups feared that a complaint could affect their status in the UK and the homeless groups felt as if complaining was futile and would not lead to change.

Mental health was thought by both groups to be grossly neglected and misunderstood. The women's groups spoke about the ongoing trauma of resettling in the UK and that this was often overlooked or not treated by health practitioners. The homeless groups felt that there was severe stigma around homeless people with mental health issues and that often treatment did not align or lend itself to the chaotic lifestyle when homeless.

Negative stereotypes were something which both research groups battled with. For the women's groups it was a distinct feeling of not belonging and being treated as foreigners and blamed for their own circumstances. The homelessness group believed that stereotypes surrounding homeless people were deeply entrenched in society and even they felt blamed for their personal circumstances as if they had chosen a homeless life, which resulted in self-stigma.

Discrimination was very present throughout all focus groups. For the homelessness groups it appeared as if discrimination was systemic, whereas the women's groups portrayed discrimination at a more individual-level. It was very apparent in the homelessness groups that they faced discrimination at every corner whilst seeking assistance.

Gender was another key issue to emerge for both groups and women in both groups experienced particular discrimination, for example homeless women who were pregnant, and felt there were often fewer services for women than for men. Local organisations played a crucial role in the lives of many participants from both groups. For the homelessness groups, the opportunity to volunteer and engage with others was seen as a crucial part of recovering from the homeless experience. For the women's groups, the opportunity to meet other women with shared experiences and share their culture and exchange information was seen as a vital part in establishing their lives and navigating the UK.

Although many issues were common, differences did emerge in the response from the two groups. Mixed experiences were expressed by the women's groups in regard to accessing and receiving healthcare. Many women believed that when they faced discrimination or negative treatment that this was due to the individual that they were dealing with, rather than being an issue of widespread discrimination. Overall, the women believed that they had positive experiences and would keep seeking medical assistance from health care professionals. The homelessness groups had largely negative experiences with only one positive story being shared about good treatment at the GP practice. Good amounts of information were being provided to refugee and asylum-seeking women upon arrival to the UK. The women's groups claimed to have a very good understanding on how to access medical services and where to register with a GP. The homeless groups found it difficult to access information on services and were often reluctant to approach services for fear of discrimination. Language

barriers presented an obvious issue for women who had recently arrived in the UK and whose command of English was insufficient to communicate with health services. The feelings toward interpreters were mixed. Finally, volunteering was highly significant to recovery and re-establishment for the homelessness group, whereas it was barely mentioned with the women's groups.

Although many issues related to service provision, what emerged from this study was the importance of wider societal factors impacting on the human rights of participants. Racism and Islamophobia were a serious concern for the women taking part in this research study. It was believed that Islamophobia was at an all-time high and prevented women from seeking help. There was a serious concern for the children of the women who participated in the research and it was stressed that the wellbeing of the children was directly linked to the health and wellbeing of the women. Discrimination appeared at all levels of society. This was particularly true for people with an experience of homelessness and it appeared the service response often reflected this wider discrimination. Crucially, the right to health was experienced as more than the mere absence of illness or disease. Both groups had a profound understanding of what it meant to be healthy and the factors that contribute to this state. The homelessness groups spoke a lot about the need for housing and security in order to obtain the highest possible standard of health. The women's groups spoke of emotional and mental health as essential to overall wellbeing and how their status as an asylum seeker undermined their sense of wellbeing.

Despite limited resources, it proved possible to conduct this research in a participatory way. The collaboration of partner organisations was a crucial success factor, making it possible to offer the peer researchers support throughout. The peer researchers themselves led the data collection and created an environment that encouraged research participants to take part and share their experiences in depth. The peer researchers themselves were able to

build on their existing skills to take part in the research and dissemination and their experiences proved invaluable in shaping and interpreting the research. The collaborative, participatory approach helped to create a reflective space in which all those involved could learn from each other. The peer researchers themselves gained confidence and skills, sometimes in unexpected ways, such as being able to finish a project they had started. Preparing for presentations together after the research had been completed and taking part in dissemination events provided an important opportunity for the peer researchers to realise what they had achieved individually and collectively and to receive feedback.

The report suggests that we should think fundamentally about how we design healthcare provision to meet the needs and realise the health rights of those who are most excluded. A key issue for improvement is the lack of flexibility of services when people have chaotic lives and the need for holistic and one-stop services. There are examples of how a rights-based approach has led to fundamental changes in services and wider social supports for those who are excluded, for example the Housing First model developed in the US. There is a need to develop approaches to service delivery that are more rights-based and the renewed drive towards integration in Scotland provides an opportunity to develop services in a way that acknowledges the impact of social determinants of poor health and addresses holistic needs through an emphasis on promoting rights within a preventative public health framework. Furthermore, this study highlights the value of participatory and peer-led models, which acknowledge the value of lived experience, as being essential to realising the right to health in Scotland.

Recommendations

A number of key recommendations emerge from the findings of this study, which have implications for policy makers and service providers. Several of these are quite specific and relate to enhancing the PANEL themes:

<u>Participation</u>

- Promote volunteering opportunities, especially for those who have experienced homelessness.
- Provide advocacy support in to help people know their rights.
- Promote the participation of people with lived experience of homelessness and other forms of exclusion in NHS staff training and conferences.
- Mainstream the training and employment of peer workers within services.
- Provide information packs to all new patients registering with a GP that inform people of their rights and the care they are entitled to.

<u>Accountability</u>

- Provide feedback forms at primary care services which can be completed anonymously and without having to request them from the receptionist, voluntary providers etc.
- Promote awareness of the complaints process amongst people with lived experience of homelessness and the provision of advocacy support in making complaints.

<u>Non-Discrimination</u>
- Challenge racism and religious prejudice especially Islamophobia within NHS services and via opinion formers and the media.
- Tackle discrimination and stigma through training led by people with lived experience and strengthen complaints processes, learning from other areas such as mental health stigma programmes.
- Provide training to NHS staff on the impact of asylum seeking on health, including specific training to GPs on dealing with trauma.
- The impact of asylum system on mental health needs to be acknowledged and addressed by the Home Office.

<u>Empowerment</u>

- Promote knowledge of rights and how to claim rights – this information must be made accessible and engaging as currently it is not.
- Make the language of human rights more accessible and demonstrate how people can utilise the concepts in everyday life.
- Extend and sustain funding for women's support groups and organisations.

And identify and test potential service improvements which can be summarised under the AAAQ framework, for example:

Availability

- Longer appointments for those with complex needs to provide the opportunity for more person centred practice.

Accessibility

- Improve access to information, including information about rights, through the provision of a one-stop shop and signposting by health, social care and housing practitioners.

Acceptability

- Improve practice on the use of interpreters so people get the assistance they want.

Quality

- Develop better mental health outreach support for people with lived experience of homelessness.

Dissemination

This is an action research project and as such, from the start there was an explicit plan to disseminate the findings to ensure that they could inform policy in Scotland on health and human rights. The dissemination process reflects the participatory and partnership ethos of the project and involves different partner organisations (University of Strathclyde, the Health and Social Care Alliance Scotland, Glasgow Homelessness Network and the Mental Health Foundation) and each event involves presentations by peer researchers involved in the project with lived experience of either homelessness or asylum seeking.

The project steering group will also work with NHS Health Scotland and Scottish Government to ensure the research informs future policy and strategy on health and human rights in Scotland and make connections with international work in this area.

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Appendices

Appendix A: Members of Steering Group

Amal Azzudin, Mental Health Foundation

Julie Cameron, Mental Health Foundation

Kevin Campbell, NHS Health Scotland

Lisa Curtice, Health and Social Care Alliance Scotland

Claire Frew, Glasgow Homelessness Network

Jenn Glinski, University of Strathclyde

Lee Knifton, Centre for Health Policy, University of Strathclyde

Neil Quinn, Centre for Health Policy, University of Strathclyde

Appendix B: Focus Group Schedule: Glasgow Homelessness Network

Activities (Duration: Max 2.5 hours)

1. Introductions and welcome (15 min)
   - Information about the project
   - Information about health and human rights
2. Images as icebreaker activity followed by discussion (1 hr)
   - Larger discussion following from the icebreaker with set of general questions
3. 1 on 1 interviews with willing participants with set of specific questions (15-20 min)
4. Evaluation, monitoring forms and thanks (5 min)

Questions for Focus Group

Participation
- What do you think of when you hear the words "human rights"? What does it mean to you?
- What does "the right to health" mean to you?
- How easy is/ was it for you to find and access health services as a homeless person/ when you were homeless?*
   - Did you feel welcome when you went in?
   - Were you listened to by the staff?

Prompts:
Do you feel like you have the opportunity to participate in all decisions about the care and support you are receiving?

Accountability

- If you could change anything about using services, what would it be?
- How can services improve to better suit the needs and concerns of those people experiencing homelessness?

Prompts:

Who do you think is responsible for ensuring that you are respected, protected and that your human rights are fulfilled?

Non-Discrimination

Do you think your right to health is affected by homelessness? How so?
Do you feel discriminated against when accessing health services?

Prompts:

Do you believe that all of your identities (what makes you, you) is being protected and respected when you think of your health? (sexuality, gender, ethnicity, religion, etc.)

Empowerment

- Do you think people know that they have human rights?
- Do you feel healthy today? What could make you healthier?
- Do you know what to do if you have experienced discrimination when accessing your right to health?
- When you have accessed health services were you told about your rights? (e.g. complaints procedures, right to access, acceptability, availability and quality of care)
- Are you aware that there are speciality health services for people experiencing homelessness?

Legality

- Did you know that it is illegal to breach your human rights?

Thanking them for participation and their time. Tell participants how this information will be used and follow-up with one on one interviews.

Appendix C: One-to-One Interview Schedule - Glasgow Homelessness Network

Introduction, welcome and thank you.

1. Do you think your ethnicity affects you when accessing services?

2. Are you accessing any other services?

3. What are your priorities in your day to day life and in regards to your health?

4. Have you at times sacrificed your health and wellbeing?

5. Has anything stopped you from getting accommodation and achieving good health / wellbeing?

6. Has your postcode affected you accessing services?
   - Have you ever had to relocate to another postcode to access services?

7. Is there anything else you would like to share with me?

Thank participants for their time and tell them how this information will be used.

Appendix D: Peer Researcher Debrief Form - Glasgow Homelessness Network

Name: Date: Venue:

No of participants: Completed consent forms:

Completed monitoring forms: Completed how did we do forms:

How did you find that?

Key themes – Health and Human Rights

Any concerns?

Reflections on your role in the research

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Any action required?

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My learning - what surprised me, any change of views?

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Appendix E: Focus Group Schedule - Mental Health Foundation

Duration: Max 2 hours

Display materials about human rights and some of the images

Introductions and welcome (10-15 min)

(To put people at their ease)

- Each peer researcher introduces themselves briefly including something about themselves (e.g. something funny)
- We are doing this research because people need to be aware of their human rights and what it means for their health.
- You only need to share what you want to share.
- Researchers to say more about the research and how it will be used to make a difference.
    - Discuss the consent form with participants.
- Ask each person to introduce themselves briefly: name, where they are from and one thing about themselves

Icebreaker (cards)

Researcher gives some information about human rights.

Then ask everyone to pick a cards to show what human rights/right to health means to them. (Give an example)

Ask people to say why they chose those images and lead a discussion about the right to health and what it means to you.

Questions for Discussion Group

1. What do you think of when you hear the words "human rights"?
    - Do you think people know that they have human rights?
    - What does "the right to health" mean to you?

2. Do you feel discriminated against when accessing health services? **(Non discrimination)**
    - How did that make you feel?
    - Do you believe that what makes you you) is being protected and respected when you think about your health (sexuality, gender, ethnicity, religion)
    - Do you feel as if you are a priority because of the experiences that brought you to be a refugee or asylum seeker?
    - Do you think your right to health is affected by your status? How so?

    Prompts: mental health, choice

3. Do you know what to do if you have experienced discrimination when accessing your right to health? **(Participation and Empowerment)**

4. How easy is/ was it for you to find and access health services as a refugee or asylum seeker?
    - Did you feel welcome when you went in?
    - Were you listened to by the staff?

    Prompts: GP, clinics, dentist, hospital

5. Have you at times given up on your health and wellbeing for something else? Why? How?

6. Do you feel as though you have the opportunity to participate in all decisions about the care and support you are receiving? **(Participation)**
    - What do you do to keep yourself well?

7. When you have accessed health services were you told about your rights? (e.g. complaints procedures, right to access, acceptability, availability and quality of care) **(Empowerment)**

8. Do you feel that your right to health has been violated? (**Legality**)
    - Did you know that it is illegal to breach your human rights?

Appendix F: Peer research training day -

Mental Health Foundation

Your invitation to
Health and Human Rights Research Training

When: Monday 29th June, 10 am to 4 pm

Where: Dewar Room

The Albany Centre

44 Ashley Street

Glasgow

G3 6DS

Buses 6, 6A

Short walk from St. George's Cross subway station

What we will do:

- Share ideas of what we want to find out
- Learn about ways we can find out the information
- Decide who will do what
- Make a plan together for our project

What do you need? Just bring yourself and be there for 10 am.

Lunch will be provided.

Human Rights Participatory Research
Training for Peer Researchers
29th June 2015, Albany Centre

Health and human rights

On the flip chart were the words that Jenn had used at the first meeting to remind us about the human rights approach:

Participation

Accountability

Non-discrimination

Empowerment

Legality.

Lisa had put some picture cards on the table. She asked everyone to pick one that 'spoke' to them about human rights. Jann had made her choice as soon as we came into the room!

These are the images we chose:

Image
Tree in hand
Hands/sunset
Lamp in forest
Lightbulb

Scales of justice
Ball and chain
Intertwined strings

Each person then explained why they had chosen that image and what it meant to them. The others in the group then offered comments on what they saw in the image.

The group agreed that asking people to pick a picture and talk about it was a good way to start a conversation. It showed that people had different experiences. On the other hand, it also brought out connections between people. It was relaxed and gave you a choice about how much to say about yourself. We then tried out another kind of icebreaker that was a bit more personal.

Lisa explained about Dr Kate Granger's [#hello my name is…](#) campaign and then everyone took a form that asked them to fill in:

Hello, my name is….

I am passionate about …

You can ask me about ….

We introduced each other in pairs and then everyone was introduced to the group. The form was a bit confusing! Not everyone was clear what to put under 'you can ask me about…' Lisa explained it was for things you knew about or were good at, especially things other people might not realise you could do! Also the form is for people to describe themselves and we ended up introducing another person to the group! Anyway, we made it work and learned things about the people in the room.
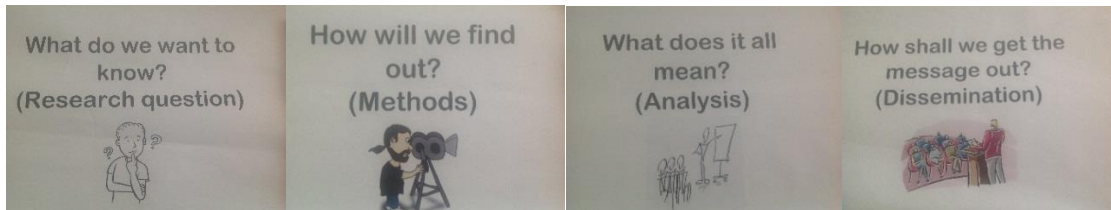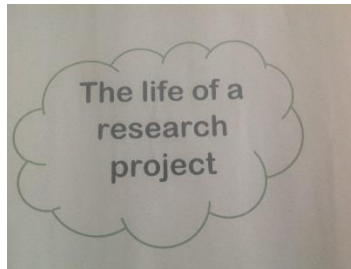
What we need to pay attention to (ethics):

We talked about the things we would need to be careful about to keep the people we met safe and comfortable. This was our list.

- Be compassionate/show empathy
- Listen
- Put people at ease, they are in control
- Respect their opinion
- Not be judgemental
- Be polite
- Be professional – the research role is different from advocacy. Our primary job is to listen and not to get involved or share our own experience, though we can signpost people to other support where appropriate.
- Confidentiality
  - No names
  - Not too much detail
  - Anonymous
- Give people a choice to take part
  - "Non-coercive"

- Not to do harm
    - Offer support and information
    - What to give back?

This led to an action:

- Prepare an information sheet for participants.

Jenn will also be writing an application to the University of Strathclyde for them to check that our research will be safe for people to take part. We need this agreement before we can start approaching groups. This is called getting ethical permission for the research.
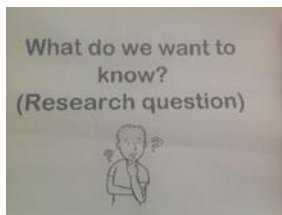
Aims

Next we thought about what we want to know. We can think of this as the aims of our study or the research questions.

- What do people know about human rights?
- What does human rights and health mean? (different groups)
- Barriers to access to NHS
- What changes do you want?
- How to get more participation in health
- What works well?
- Some solutions/recommendations.

Who?

We talked about the importance of rights for all people from ethnic minorities. We agreed that this was important but that our focus now is on:

    - Refugees, and
    - Asylum seekers
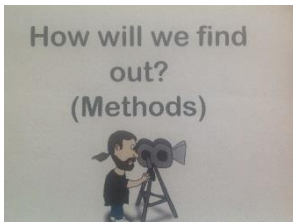
<u>Gender</u>

- Allow for separate groups
- Some mixed

<u>Age</u>

- A range including some young people aged over 18 if possible.

<u>Ethnicity</u>

- Mixed

We talked about the groups we could approach to fond people to take part in the research. Some people may attend several groups.

How many?

We will aim to speak to up to about 40 people.

How will we do the research?

A group session with the possibility of some individual interviews to get individual stories

One to one interviews

Good for:

In-depth conversation
Individual story and views

BUT
Take time
Need to record as well as talk
Lots of information

Groups

Good for:
- Peer talk
- Doing things

Listening to how people talk together

✓✓
- shared experiences
- may spark each other off

BUT
- may lose individual stories/views
- recording can be tricky

Session outline

Icebreaker - what is human rights in your language?

Discussion on what do you understand by human rights? (We talked about whether people would need some explanation and we decided that it would be important to find out first what people understood themselves.)

<u>What does human rights mean to you?</u>

To find this out we will use the image cards and say 'pick one that speaks to you about human rights'. We would then ask people to say why they had picked that card and invite other members of the group to speak about that image too.

<u>Health and human rights</u>

We then need to focus on human rights in relation to health. We talked about how to do this. A suggestion was a set of images that were more specifically about health.

To focus on access issues we thought it would be good to act out a small scene, for example someone coming to a GP receptionist and being fobbed off. We will then ask the group 'what would you do next?'.

During the discussion the researchers would have a set of questions (topic guide) that they would use to prompt and focus the discussion including:

<u>Set of questions</u>
- Experience – what has your experience been?
- Feel – how does this make you feel?
- Barriers – what barriers have you come up against?
- What would like to change?
- [we forgot to include participation on this list, for example, have you been asked to take part in making health services better? How could you be involved…]

Neil suggested that the PANEL principles (see page 2) could help to structure discussion also.

A record of the session

Lisa said it was worth thinking about how to create a record of the discussion as it went by using creative tools: for example -

Ways to help make a record
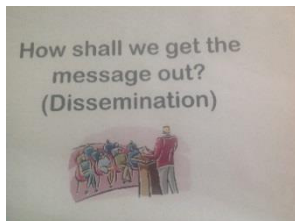
Flip chart

Speech bubbles & post-its

and cakes!

Groups- doing things that create a record

http://pphw.alliance-scotland.org.uk/co-production/asset-mapping/

Getting the message out

How shall we get the message out? (Dissemination)

We talked about how important it is to the group that this work makes a difference to people. We could use drama and images to 'tell the story'. Lisa showed a picture of an object from an interfaith exhibition about domestic violence and suggested that one way to tell a story is through significant objects and why people say they matter to them. We could do this during the research.

I love these shoes but they hurt me now

Also we will have the chance after the research to put together different ways of getting the message out there. This could include drama, such as forum theatre, where a scene is acted out and then people are invited to come up and change what happens to show how things could be different. We watched a video clip of a 'digital story' where someone tells their story through voiceover and images
http://www.bbc.co.uk/wales/audiovideo/sites/yourvideo/pages/yusef_y_01.shtml

Appendix G: Peer research training day -

Glasgow Homelessness Network

Your invitation to
Health and Human Rights Research Training

When: Tuesday 30th June, 10 am to 4 pm

Where: Health and Social Care Alliance Scotland

Lower Ground Floor

349 Bath Street, Glasgow

G2 4AA (close to King's Theatre and Charing

Cross Station)

Buses 3, 42, 42A, 4, 4A

What we will do:

- Share ideas of what we want to find out
- Learn about ways we can find out the information
- Decide who will do what
- Make a plan together for our project

What do you need? Just bring yourself and be there for 10 am.

Lunch will be provided.

Health & Human Rights Participatory Research Training 30th June 2015, Venlaw Building

Glasgow Homelessness Network - Notes
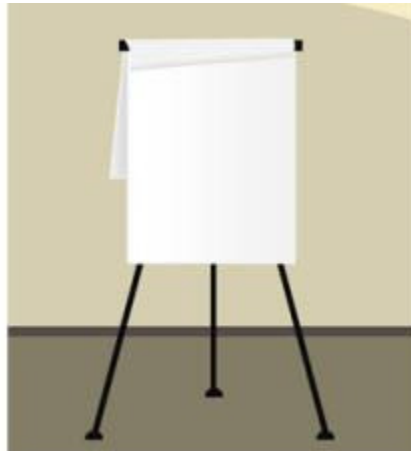
Health and
Human Rights
Participation
Accountability
Non-
discrimination
Empowerment
Legality

Welcome to the peer researchers

Neil welcomed everyone. He said today is about finding out about research and working out a plan for how we will do it together. Our subject is health and human rights. We want this to be research that will make a difference ('action research'). It is great that everyone is so enthusiastic. We will do the research together ('participatory research').

What does health and human rights mean to us?

There were pictures on the table. Everyone picked an image that spoke to them about health and human rights. Then each person spoke about why they had chosen that image and what it meant to them. Other members of the group also said what that particular image said to them. In this way we discovered many connections, but also that experiences are different for each person. These were the images we chose:

Tree in hand
Sun/water
Welcome mat
Birds
Hand print
Lighthouse
Hands
Jigsaw

Key words from the discussion included: safety, wellbeing and perspective, hope, no judgement, belonging – "I'm a part of this", fitting in, trust, freedom – "a bird in a cage with the door open", strengths, not being a burden, responsibility, not for self, barriers, overcoming shame and pride, light in the dark, silence and peace, awe struck by nature, connecting communities and services. We agreed that pictures were a safe way to start a conversation in the group.

Who was in the room?

The next activity was to find out more about the people in the room and the passions, skills and experience they bring. Lisa introduced the #hello my name is… campaign, started by Dr Kate Granger, a young doctor who is dying, and wants to get all NHS staff to introduce themselves by name to patients. Everyone had a go at filling in a sheet that asked:

My name is …

I am passionate about …

You can ask me about …

My role …

We shared this information in pairs and then fed back to the whole group. It was a bit confusing using the form to introduce someone else! But we learnt that everyone in the group is passionate about making a difference to others. Experiences and include volunteering and advocacy, knowing how to help others. We also found out some things we didn't necessarily know. One person loves ballet and another knows lots about 80s pop music! We have at least one singer! We have a variety of roles in life including being a parent. One person described themselves as "a human bridge".

The life of a research project

On the wall were flip charts to remind us of the different stages of a research project. Later we added a new one at the beginning – preparation!
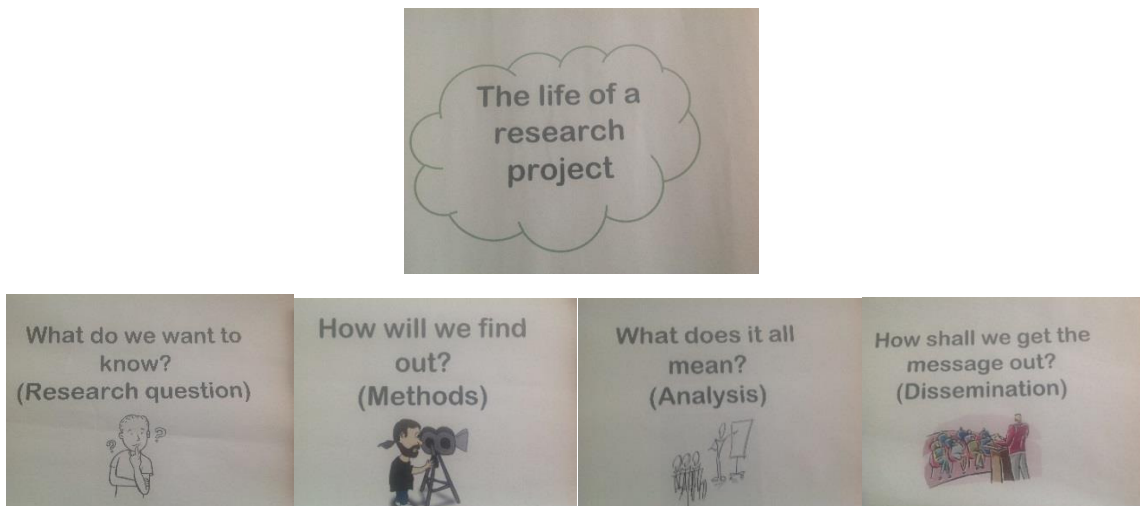
Preparation
- Information pack
  - Support and services available
- Information about research

- o Anonymity
- o Confidentiality
- o How will information be used
- o Why/what the research is for
- o What to expect - Could present this as circles to show journey of project

- Introductory letter with bios of the researchers
- Thank you letter
  - o Reassurance
- Practise role?
- Offer choice of interviewer
  - o Gender
- Feedback form
  - o Questions about interview to improve as we go

Ethics

We then considered how to ensure the wellbeing of the people we will ask to take part in the research. What do we need to do/not do and pay attention to (ethics)

Pay attention to
- Signpost to info/support
- Give them something back – e.g. at the end hold an informal, 'natural' event to share the results, for example in a park
- Let them tell you what they are comfortable with
- Set the scene
- Do no harm
  - o Prepare
  - o Choice – gender
  - o Access to support

- Let person be in control
- Tell them what is involved
  - Bio of interviewer

- Make them comfortable
- Clear role
- Tell them why and how information will be used
- Anonymity/let them choose name to call then in the report
- Hold back passion
- Confidential
- Thank you letter

This discussion gave us a clear list of things to remember when we are carrying out the research.

- Be clear about our role
- Confidentiality
- Anonymity
- Make them comfortable/let them be in control
- Safe environment
- Show person is valued

Neil explained that the University of Strathclyde where he and Jenn work will need to check that we have thought about all this. Jenn has to make an application (ethics submission) before we can start contacting groups to take part.
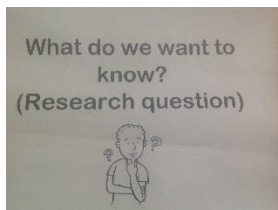
Research Question

Next we moved on to planning for the first stage of the research. This is saying what it is that we want to know –

our aims for this project.

<u>Our aims</u>

What do we want to know?

- Access to health services
    - ○ Barriers
    - ○ Enablers
    - ○ Which services?
    - ○ What has worked?
    - ○ Availability (e.g. out of hours)
- What does human rights mean to you?
- Do people know they have human rights?
- What is the right to health?
- When people accessed services were they told about/given rights (e.g. complaints procedure)?
- Do they feel healthy?
    - ○ Why/why not?
    - ○ Outcomes – what is healthier?

Neil suggested that the human rights principles could provide a framework for the questions to be asked.

<u>PANEL</u>

Participation

- How could it be increased?
- Do people feel involved (in care)?
- Sense of value
- Comfortable
- Ever asked?

Accountability

- Whose responsibility?
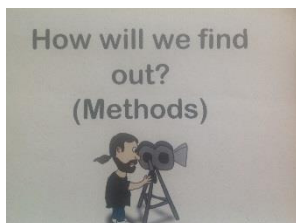
Non-discrimination

- How does it feel?
- "Culture"
- 'Homeless' identity/stigma (labelling)
  - Why?
  - Does it stop you going to services?

Empowerment

- Offered opportunities to develop?
  - Information sharing
- Changes that would make a difference?
  - Ideas
- Journey
  - Invite back

Legality

- Do you know your rights?
- Why discriminated against?
- Do you know where to go?
  - Legal advice

Methods (How will we find out?)

The next big task we tackled was how we will find out the information we want to know. Lisa showed some slides about ways of doing research (methods). She said it is important to do things that create a record of what people are saying. Lisa showed some slides about ways of doing research (methods).

One to one interviews

Good for:

In-depth conversation
Individual story and views

BUT
Take time
Need to record as well as talk
Lots of information

Groups

Good for:
- Peer talk
- Doing things

Listening to how people talk together

✓✓
- shared experiences
- may spark each other off

BUT
- may lose individual
  stories/views
- recording can be tricky

She said it is important to do things that create a record of what people are saying.

Ways to help make a record

Flip chart

Speech bubbles & post-its

and cakes!

Groups- doing things that create a record

http://pphw.alliance-scotland.org.uk/co-production/asset-mapping/

How many people think that?

http://blogs.iriss.org.uk/keepingitpersonal/

Not to forget also that it is possible to count how many people agree or disagree with something in the group eg by having a vote.

Our methods

For this research the group decided on

    A. Group discussions (focus groups) in settings where this is possible

    B. Brief interviews with a very short from for the researcher to complete in places like day centres that are very busy.

We had lots of ideas of things we could do in groups. We liked the idea of having activities as a way of getting conversations going.

Focus Group

- Hostel/supported accommodation
  - Group setting
    - Image/ice breaker
    - Talking wall/story
    - Small group
    - Comments box
    - Interactive focus group
    - Raffle of rights
    - Role play/acting
    - Collect some basic info <u>at the end</u> about circumstances of people in the group
- Day centre
  - One-to-one – short interviews
    - Time line – accommodation
    - Structured
    - Have a single sheet to fill in
      - ❖ Where are you currently?
      - ❖ Then fill in for all stages
      - ❖ Different stages of journey

1- 10 + Comment	Rough sleeper	Hostel	Etc (different stages)
How healthy feel?			
How easy to access health services?			
What makes you feel well?			

Neil explained that Jenn will support the researchers and probably come with them on research visits.

Who?

Then we had to decide who we were going to invite to take part in the research. Here is what we decided:

Our focus is on homeless people
- There is a legal definition of homelessness
  - o Inclusive – keep to that
  - o Possible sub groups
    - ▪ Mental health issues
    - ▪ Addiction issues
    - ▪ Women

Categories/stages

We want to cover a range of experiences of homelessness:

- Hidden homeless
- Rough sleepers
- Hostel
- Supported accommodation
- Day centres

<u>Possible places to find people</u>

Probably meet too many types of people:

- Food banks

Need to make sure where we are interviewing people is a good environment. We could keep a table of the kinds of people we have met at each place so we know if we are missing particular experiences that we need to try and find next

Example:

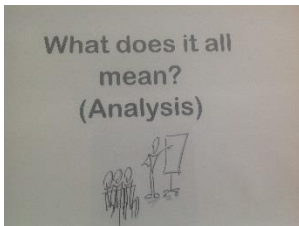|	Women	Men	BME	LGBT	Total
Place A	2	3	2	1	5
Place B	0	5	1	2	5
Place C	4	1	3	0	5
Overall Totals	6	9	6	3	15

<u>How many settings/services?</u>

- 6-8

<u>Numbers</u>

About 40 people in all.

Analysis

<u>What does it all mean?</u>

- We will get lots of information
- It is important to label everything right away
  - Date/what/who
- Check some findings back with participants?
- We can summarise findings in a table so we can all discuss them.
- It will also let us see what the others are hearing in their groups

Theme:	Meaning of Human Rights	Discrimination	
Group 1			
Group 2			
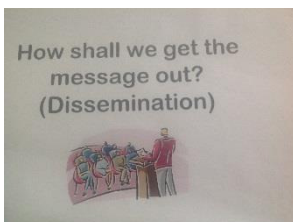
Dissemination

<u>How shall we get the message out?</u>

Lisa presented some options for telling the story of the research in creative ways.

Telling the stories
pictures, cartoons, sound, drama

http://www.bbc.co.uk/wales/audiovideo/sites/yourvideo/pages/yusef_y_01.shtml

Neil showed a video clip of a 'digital story' where someone can tell their story in pictures and sound. The group liked this and the idea of learning how to do it.

You can see it here:

http://interactions.eldis.org/urbanisation-and-health/country-profiles/kenya/digital-stories

These are the ideas we came up with about telling others about the messages from the research:

- Give something back
- Closing event
  - Informal
  - In park
- Drama
- Hand written articles
- Blogs
- Digital storytelling
- Letters

Feedback

At the end everyone completed a speech bubble with their hope for the project.

A hope for the Health & Human Rights Research Project

- That the project will improve the lives of homeless people in Glasgow & Scotland

- My hope for this project is that I learn more about people's experiences of health and human rights; that research participants are reminded (or learn) about their rights in the process and that volunteers build and develop new skills that they can use in the future.

- To gain more experience in helping homeless people to trust, access services and know their rights!

- Like to learn from this project and that the information collected can help others to learn about and improve upon health and human rights.

- Give individuals better understanding of their rights to better health care, whether they are homeless or not.

- I hope this group will be recognised for a real contribution to raising awareness of importance of HR for homeless people

- That this project brings different people together and raises more awareness of social stigma and basic human rights we are all fundamentally entitled to. Giving people hope & a voice. Help me to develop life & people skills for future use.

- To have fun, learn and to be able to educate on our data collecting journey as well as be able to collect some really useful voices and journeys to shape a really effective outcome resource.

Action plan

What we need to do next

action plan

Timeline

- July – pre work and ethics
- August (end of) – contact groups
- September/October – collecting data
- November/December – analysis
- January/February – event

Actions

- Update Douglas about today (David)
- Update Jenn (Neil)
- Write up flipcharts (Lisa)
- Meet next week and chose from all our ideas about how to do the research.

Appendix H: The Peer Researchers

Jaan Abdulkadir

Jaan is a volunteer with the Mental Health Foundation Scotland who believes that women who are refugees and asylum seekers have the right to better support. She wants everyone to have access to high quality health services and to be treated with respect.

Alan Buick

Alan is a volunteer advocate with Navigate at Glasgow Homelessness Network. He says:

"I've had recent experience of being homeless and was surprised to find that my health went in to decline and I didn't know anything about my human rights at the time but received help from mostly charity organisations which allowed me to appreciate the benefits of both."

Mhurai Dzingisai

Mhurai is a volunteer with the Mental Health Foundation Scotland.
She cares about the health of others, especially those who cannot look after themselves. She took part in the research to fight inhumanity and stand up for people's rights.

Duncan Easton

Duncan is a volunteer advocate with Navigate at Glasgow Homelessness Network. He says:

"Helping others is my passion. I am involved in this research to get a better understanding of human rights, and for homeless people to gain a better understanding of the things they are entitled to i.e. health care, secure and safe accommodation that is sustainable."

Derek Holliday

Derek is a volunteer advocate with Navigate at Glasgow Homelessness Network. He says:

"I passionately believe that everyone irrespective of your journey or current circumstance in life, should always be included, supported and given every chance to be part of your community and society. Everyone has something to offer, share or untapped potential waiting to be opened and no plight should ever be a continuous wall to shut you out and exclude you from hope! I spent large parts of my childhood & life being told I couldn't achieve anything, by family, friends, teachers, peers and those who should have supported me.

What I have learned in my life thus far. "Is that it is never too late to be what you could have been." I guess it is why I all always believe that anything is possible, you have one life and nobody can dump there issues or ignorance onto you in the hope that it holds you back or down. Stand up for your rights!"

Douglas McLaughlin

Douglas is a volunteer advocate with Navigate at Glasgow Homelessness Network. He says:

"I am glad to be part of this research as I would like to see a change in the way those affected by homelessness are seen and treated by services and organisations, and also in society.

In my spare time I enjoy cycling, on and off-road, and I enjoy cooking and hosting small dinner parties"

Appendix I: Dissemination plan

The dissemination plan has involved presenting at the following events:

1) Scottish Government/NHS Health Scotland seminar on health and human rights, Edinburgh, January 2016

2) Health and Social Care Alliance Scotland, "People Power: Creating the Conditions for Change" conference, Perth, February 2016

3) NHS Health Scotland Health and homelessness conference, Edinburgh, March 2016

4) SNAP Health and Social Care steering group, Edinburgh, April 2016

5) University of Strathclyde Engage Week event, Conversations in health policy, Glasgow, May 2016

6) Voluntary Health Scotland conference on health inequalities, Stirling, June 2016

7) Right to Health event, in partnership with Health and Social Care Academy, with SNAP, launch of report and film, Glasgow, 26 August 2016

8) University of Strathclyde Centre for Health Policy International Seminar Series, August 2016

#righttohealth

Centre for Health Policy, University of Strathclyde

https://www.strath.ac.uk/research/internationalpublicp

olicyinstitute/centreforhealthpolicy

Health and Social Care Alliance Scotland

http://www.alliance-scotland.org.uk

http://academy.alliance-scotland.org.uk/

Twitter: @ALLIANCEScot @HandSCAcademy