

# the lived experience of loneliness and social isolation in Scotland



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I am the Policy Engagement Officer at Voluntary Health Scotland and joined the VHS team in September 2016. I was previously employed by the Scottish Independent Advocacy Alliance, Citizens Advice Scotland and the Scottish Council for Voluntary Organisations in various roles involving policy, research and communications. Through my role in VHS, I have been involved in a range of activities aimed at raising awareness and understanding of loneliness and social isolation as a public health issue as well as helping to support the development of the Scottish Government draft strategy, A Connected Scotland. It was through this that I identified a number of gaps in the existing research and decided to undertake this piece of work in order to gain an insight into people's lived experience of loneliness and social isolation and what they think the solutions are. The findings of the research were also used to respond to the Scottish Government Consultation on the draft strategy, A Connected Scotland.

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# **Voluntary Health Scotland**

Voluntary Health Scotland (VHS) is the national intermediary and network for voluntary health organisations in Scotland. We work with our members and others to address health inequalities and to help people and communities live healthier and fairer lives.

VHS's interest in loneliness and social isolation started through our work around health inequalities. In 2015 VHS conducted research into the voluntary health sector perspective on tackling health inequalities, Living In The Gap, in which 90% of participants identified loneliness as both a determinant and symptom of health inequalities. In our 2016 membership survey, 86% of respondents rated the impact of social isolation and loneliness on health as an important work area for VHS to develop. Since then we have held a conference on the subject, 'Loneliness: A Threat to Health', as well as a seminar that engaged third sector and Scottish Government in an early discussion to explore what a national strategy on loneliness and social isolation needed to address. We have worked with a range of organisations and held a number of events and roundtable meetings in order to help shape discussion around the draft Scottish Government strategy, A Connected Scotland.

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#### Introduction

Voluntary Health Scotland (VHS) conducted a qualitative study to investigate the loneliness and social isolation experienced by under-represented demographics in Scotland who often face multiple triggers including, socio-economic disadvantage, poor access to transport and a lack of places and spaces that encourage connectedness and foster belonging. The research was conducted with women from Black and Minority Ethnic (BAME) backgrounds, people living in a socio-economically deprived area (who may not all be socio-economically deprived themselves but are impacted by the environments in which they live), people living and working in rural communities and paid and unpaid carers of people receiving palliative care.

The intention of the research is to highlight perspectives and voices on loneliness and social isolation which are not often heard and use these to produce a clear and informed understanding of what loneliness and social isolation is, what causes it, why for some it becomes chronic and what can be done at an individual, societal and governmental level to tackle it.

The report allows readers to identify key areas that relate to their own individual or organisational areas of interest and work, such as transport, older people or the welfare system, for example, and gives them an opportunity to explore these in the context of loneliness and social isolation. The report also provides policy recommendations for decisions makers seeking to tackle loneliness and social isolation.

The report is split into three main sections. The first section seeks to illuminate the experiences of loneliness and social isolation felt by underrepresented demographics and the issues, triggers and life circumstances participants have identified, that underpin these. It also aims to define loneliness and social isolation and its relationship with mental health, inequalities and power.

The second section looks to understand the importance of place and place based approaches, which have been identified by participants as having a key role in instilling a sense of belonging, giving people a sense of purpose and creating more connected communities' thus reducing loneliness and social isolation.

The final section aims to discuss key policy areas identified by participants when asked what the Scottish Government can do to enable social connectedness and reduce loneliness and social isolation.

#### **Key Findings**

- Loneliness and social isolation is a Public Health issue. It affects all population groups impacting on their quality of life, resulting in a range of poor and often life limiting physical health conditions and driving down people's mental health and wellbeing.
- Loneliness and social isolation is often triggered, exacerbated and maintained by the social and economic circumstances in which people live including the level of resources such as financial power, knowledge and social capacity that are

- available to them. Those who are already at risk of being marginalised have a greater likelihood of experiencing chronic loneliness and social isolation and the associated mental and physical health outcomes.
- Places and spaces are central to tackling loneliness and social isolation as they
  encompass both the physical environment where social contact occurs such as
  our homes, streets, public areas, natural spaces and the mobility of people
  across these as well as the social environment that is the relationships, social
  contact and support networks that exist within a place. Places, spaces and the
  links between them that are well- informed by those that will use them, welldesigned, maintained and resourced, are key to nurturing quality relationships
  and developing a sense of belonging and purpose.
- Activities that focus on a sense of community help to foster strong bonds. People
  do not want to be passive recipients of services, they want opportunities to
  engage in reciprocal activities that work towards a common goal and allow them
  to contribute to their communities. These are important in instilling a sense of
  purpose and belonging and strengthening social ties on an equal basis.
- Understanding the nature and importance of compassion not only in our roles
  within health and care but in all services provided to the public, regardless of the
  sector delivering them, is key to ensuring people feel they are understood,
  respected and that they matter. That is to see the person not a label, to
  recognise people's lived experience and circumstances and to try to take action
  to reduce their problem or distress.
- Loneliness and social isolation cut across all six national public health priorities<sup>12</sup> but also a range of multidisciplinary and cross-portfolio policies and legislation.
   There is a need for an enabling Government that recognises its role in delivering policies and strategies that tackle socio-economic inequalities within our society, give people their right to health and wellbeing and invest in those with the least power.

#### Methodology

The research was conducted by VHS Policy and Engagement Officer, Kiren Zubairi and the report was compiled and finalised with advice and guidance from the VHS Chief Executive Claire Stevens and members of the VHS Board.

A mixed methods approach was adopted, comprising of a short context review, focus groups and semi-structured interviews. In March 2018, we conducted 5 focus groups and 6 interviews speaking to a total of 57 people. We spoke to service users as well as service providers to try and understand people's experiences of loneliness and social isolation and what they felt the Scottish Government's, organisations' and society's role should be in tackling the issues. The research participants were part of VHS's membership and included Nari Kallyan Shango, Cope Scotland, The

<sup>2</sup> The Public Health Priorities include; vibrant, healthy and safe places and communities; flourish in our early years; good mental wellbeing; reduce the use of and harm from alcohol, tobacco and other drugs; develop a sustainable, inclusive economy and healthy weight and are physically active.

<sup>&</sup>lt;sup>1</sup> Scottish Government (2018). Scotland's public health priorities

Conservation Volunteers, Marie Curie Hospice Glasgow and Marie Curie Expert Voices Group.

A discussion guide was produced to support the focus groups and is available in Appendix 1. The process also involved conducting a focus group in Urdu and translating and transcribing to English for use in the report. A short questionnaire to prompt discussion during the interviews was developed, however, we let the discussion flow naturally and allowed participants to self-identify and raise issues themselves. The Questionnaire is available in Appendix 2. A copy of the participant information sheet and consent form are available in Appendix 3 and 4 respectively.

Desk based research was conducted to compile a short context review to try and add depth and background to the issues and solutions that participants raised.

# Why is it important to recognise and understand the perspective of underrepresented demographics?

Loneliness and social isolation can be experienced by anyone at any time in their life. However, loneliness and social isolation can often become compounded for certain demographics within our society, many of whom are not often represented in the mainstream.

In our research we have tried to capture the experiences of a range of different demographics to gain a holistic understanding of loneliness and social isolation and the environments, triggers and circumstances that foster these. We have spoken to women from Black and Minority Ethnic (BAME) backgrounds, people living in a socio-economically deprived area, people living and working in rural communities and paid and unpaid carers of people receiving palliative care.

Although this is a diverse group of people the findings reflect that participant's experiences of loneliness and social isolation as well as the underpinning issues and triggers are shared. The various demographics experienced different combinations of the triggers for loneliness and social isolation in varying intensity and identified similar solutions to these.

This research has provided us with a thorough understanding of the experiences, thoughts and suggestions of what loneliness and social isolation is and what can be done at a national, local and individual level to overcome it.

So what is loneliness and social isolation: as one respondent put it, "*loneliness is like* a tree: it has many branches and leaves."

# **SECTION 1: Loneliness is like a tree: it has many branches and leaves**

The aim of this section is to illuminate the experiences of loneliness and social isolation felt by underrepresented demographics and the issues, triggers and life circumstances that underpin these. The section will look at defining loneliness and social isolation as understood and experienced by the research participants, explain the connection between loneliness, social isolation and mental health as well as the interplay between power and inequalities in perpetuating loneliness and isolation. The section will also highlight the participant's self-identified range of life stages, issues and triggers for loneliness and social isolation.

#### Loneliness and Social Isolation: is there a difference?

According to research by the University of York, 'Loneliness is a subjective feeling associated with someone's perception that their relationships with others are deficient' whereas, 'social isolation is a more objective measure of the absence of relationships, ties or contact with others'. In sum the latter can be a choice.

Ben Lazare Mijuskovic writes in Loneliness in Philosophy, Psychology, and Literature (2012) 'man has always and everywhere suffered from feelings of acute loneliness', however, it is important to recognise that loneliness means different things to different people. It is equally important to be cognizant of that fact that some people will feel lonely spending just a day alone, whilst others can go months with minimal social contact or communication and not experience any negative emotions. 'Some may be socially isolated but content with minimal social contact or actually prefer to be alone' writes Julianne Holt-Lunstad, the lead author of a 2015 report on loneliness in Perspectives on Psychological Science. 'Others may have frequent social contact but still feel lonely<sup>3</sup>.' As the Age UK Loneliness and Isolation Evidence review<sup>4</sup> also points out it is 'possible to be isolated and not lonely, and to be lonely without being isolated'.

During our research into the loneliness and social isolation experienced by underrepresented demographics, we asked our participants to tell us what they understood by the terms and they described loneliness as when "no one understands you or what you are going through", it is about "not knowing where to go for help" and "facing physical and mental barriers to interacting with others". Isolation as one participant put it – is about being "cut off from everything and everyone".

Another illuminating finding was the connection between loneliness and social isolation. Although we understand that social isolation can be a choice and that one can be socially isolated but not lonely, participants noted that one often begets the other – that loneliness is often followed by isolation or vice-versa.

The terms were not used interchangeably by research participants, but were used one after the other, for example: "you become lonely and isolated". There was a common theme of becoming introspective and withdrawing from society (isolation)

<sup>&</sup>lt;sup>3</sup> Holt-Lunstad J. (2015). Loneliness and social isolation as risk factors for mortality: a meta-analytic review. - PubMed - NCBI

<sup>&</sup>lt;sup>4</sup> Age UK. (2015). Evidence Review: Loneliness in Later Life.

after an 'incident' or 'trigger' that caused people to become lonely or feel that they no longer belong to a group or community around them.

# The tripartite relationship between loneliness, social isolation and mental health

"A guy needs somebody near him... A guy goes nuts if he ain't got nobody. Don't make a difference who the guy is, long's he's with you... I tell ya a guy gets too lonely he gets sick". Of Mice and Men

The links between loneliness and social isolation and physical health are well documented. Loneliness and social isolation are risk factors for coronary heart disease and stroke<sup>5</sup>. The impact of social connectedness on the risk of death has been compared with smoking and alcohol consumption and is said to exceed the influence of physical inactivity and obesity<sup>6</sup>, a leading public health issue in Scotland today. Research also shows the effect of loneliness and social isolation on the chances of developing dementia<sup>7</sup>. The Chief Medical Officer for Scotland, Catherine Calderwood, in her Second Annual Report<sup>8</sup> has also acknowledged the risk factors posed by loneliness and social isolation on people's health. Professor Sabina Brennan, a leading cognitive neuroscientist, of Trinity College Dublin highlights research that brought together 70 longitudinal studies over an average of 8 years covering 3.5 million participants on the impact of loneliness, social isolation and living alone. The results showed an increased likelihood of death by 26-30% for those reporting any of these issues – irrespective of age and socio-economic status<sup>9</sup>. This is strong evidence for viewing loneliness and isolation as a public health issue.

Our research has identified a tertiary relationship between physical and mental health and loneliness and social isolation; with each negatively impacting on the other, resulting in chronic loneliness and social isolation.

Participants noted a bi-directional relationship between mental health and loneliness and social isolation: where loneliness and social isolation drive down mental health and poor mental health increases loneliness and social isolation, resulting in a self-perpetuating cycle.

Many research participants highlighted that symptoms of clinical depression were often very similar to severe chronic loneliness, citing personal experiences of how the two occurred simultaneously. There is also evidence that draws the correlation between loneliness and isolation and suicide.<sup>10</sup>

The participants also noted that there is a lot of stigma around mental health which can lead to social isolation. "People pull back from normal life when it becomes

<sup>&</sup>lt;sup>5</sup> Valtorta NK, Kanaan M, Gilbody S, et al Loneliness and social isolation as risk factors for coronary heart disease and stroke: systematic review and meta-analysis of longitudinal observational studies Heart 2016:102:1009-1016

<sup>&</sup>lt;sup>6</sup> Holt-Lunstad, J., Smith, T. and Layton, J. (2010). Social Relationships and Mortality Risk: A Meta-analytic Review

<sup>&</sup>lt;sup>7</sup> Collins, E. (2014). Insights: Preventing social isolation and loneliness in older people. 25th ed. IRISS.

<sup>&</sup>lt;sup>8</sup> Scottish Government (2017). Realising Realistic Medicine

<sup>&</sup>lt;sup>9</sup> Loneliness in Scotland Summit. (2016). Befriending Networks.

<sup>&</sup>lt;sup>10</sup> R, S. (2001). Loneliness in relation to suicide ideation and parasuicide: a population-wide study.

difficult to explain their condition or situation to friends and family – it is easier to isolate yourself'.

Our research has illustrated the complex relationship between loneliness and social isolation with physical and mental health, socio-economic conditions and the environment in which people exist. It is useful to provide an insight into people's lived experience of these in order that we can develop solutions that cut to the core of the issues and adopt a preventative approach. In 1948 the World Health Organisation defined health as 'a state of complete physical, mental and social wellbeing, not merely the absence of illness or infirmity'. This is key to the contribution we can make to understanding and tackling the issues of loneliness and social isolation, which affect our mental and physical health and are in turn adversely affected by social and economic inequalities.

## Understanding loneliness and social isolation as a type of social exclusion

"Loneliness is hallmarked by an intense desire to bring the experience to a close; something which cannot be achieved by sheer willpower or by simply getting out more but only by developing intimate connections. This is far easier said than done, especially for people whose loneliness arises from a state of loss or exile or prejudice who have reason to fear or mistrust as well as long for the society of others." Olivia Laing<sup>11</sup>

There is a strong correlation between loneliness and social isolation and social exclusion, including but not limited to poverty, lack of civic engagement, use of or access to services<sup>12</sup>.

There are multiple dimensions to the experience of exclusion: the regularity of meeting with friends and relatives, taking part in social activities, self-rated physical and mental health, self-rated income and quality of local area.

Loneliness is regarded by some sociologists and psychologists as a direct result of our environment whilst others see it as more of a basic trait of our human nature. Our research indicates that it is a mix of both, we all have the natural propensity to be lonely but this is often triggered by our environment, the various stages of our lives and the circumstances these present. It is indeed our environment which can compound loneliness and isolation until it is chronic, and therefore this is where solutions and preventative activity need to focus alongside our ability to exercise power over our environment.

#### The role of power in loneliness and social isolation

In order to better understand loneliness and social isolation and to develop viable solutions we need to investigate the role of power and the interplay between power and inequalities in perpetuating loneliness and isolation across our society today. The concept of power or agency underpins the issues discussed in the rest of the paper.

<sup>&</sup>lt;sup>11</sup> The Lonely City: Adventures in the Art of Being Alone

<sup>&</sup>lt;sup>12</sup> Scharf, T. (2016). Responding to loneliness: opportunities and pitfalls. Voluntary Health Scotland

So what is power? According to the Oxford Dictionary it is simply, "the ability or capacity to do something". However, it embodies a more complex definition, the power we have within the different relationships that make up society, the power we have over our immediate conditions and circumstances and the power we have to influence the wider environment in which we exist.

A lack of power is a fundamental cause of health inequalities and is regarded as one of the three fundamental determinants of health alongside income and wealth<sup>13</sup>. It is really important to be able to have power and control over our lives and the environments in which we exist. We may be lonely, a natural phenomenon, but on top of that we do not have any power to change our circumstances and positively affect our social circumstances, the loneliness can then become chronic.

People's chances of becoming chronically lonely are greatly increased by the circumstances in which they live, and the levels of resources such as financial power, knowledge and social capacity that are available to them. Increasing people's awareness of loneliness and social isolation, their negative impacts, and highlighting actions individuals can take to reduce and prevent loneliness can actually result in widening inequalities. This is because the people with the most resources tend to be the most able to make changes to their lifestyle and immediate environment.

Civic engagement is also important as people need to be able to influence the decisions that affect them. However, evidence suggests that the proportion of people in Scotland who feel able to influence decision making in their local area has been consistently low since 2007. Only 23.6% of the Scottish population agreed with the statement 'I can influence decisions affecting my local area', in the Scottish Household Survey in 2015<sup>14</sup>. According to the Scottish Public Health Network, social inaction, characterised as a state where individuals choose to, or feel unable to, take part in social action and are disconnected from concepts of 'we-ness' and civic society, is a form of loneliness and social isolation<sup>15</sup>.

Civic engagement is also closely linked with the concept of belonging. Most of the literature that binds these ideas focuses on migration or ethnic minorities. However, our research has highlighted that people who may have been local/indigenous to an area their entire life also feel disengaged and isolated within their communities, and many do not access local services or utilise local resources due to a number of perceived barriers, which will be discussed later.

A breakdown in people's sense of purpose and a lack of connection with those around them and the community in which they live were at the core of much of the discussion participants had about loneliness and isolation and how it affects them.

#### Triggers, life stages and issues

Participants self-identified a range of life stages, issues and triggers for loneliness and social isolation: we have noted these and tried to unpick them. Whilst this

<sup>&</sup>lt;sup>13</sup> NHS Health Scotland. (2018). Power Inequalities

<sup>&</sup>lt;sup>14</sup> Scottish Government. (2015). Scotland's People Annual Report: Results from the 2015 Scottish Household Survey

<sup>&</sup>lt;sup>15</sup> McCann, A., Mackie, P., Conacher, A. (2017). Social Isolation & Loneliness: What is the Scope for Public Health Action? Scottish Public Health Network

section of the report is quite descriptive, it is imperative that we lay down the foundations of what people think loneliness and social isolation are and what life stages, environments and circumstances trigger them, in order that we can work towards realistic solutions.

# **Older People**

Older people or later life was almost always one of the first groups or triggers for loneliness and isolation identified by the research participants. Many service providers we spoke to said that they see "re-occurring instances of older people feeling lonely, many feel that it is too late for them to make new friends and develop new social interests." Participants identified the lack of family contact that older people may have, as well as an inability to access support from services and engage in activities and mobility issues, as causes of chronic loneliness and isolation amongst older people.

Although loneliness and social isolation can be experienced at any time in a person's life, participants noted that the triggers tend to coalesce frequently in later life as well as during early adulthood.

#### **Bereavement**

Bereavement was also identified as a trigger for loneliness and social isolation. Participants mentioned that the death of a close family member or friend can result in people feeling lonely but can also cause people to become isolated as they no longer have the same level of social contact.

"I know someone whose husband of 50 years died; although she is 83 she is very fit and physically healthy but instead of going out and meeting people and doing things she stays in her bed all day and has not been over the door since her husband died".

"We had a situation where a gentleman's wife had arranged all their social interactions and now that she has passed he has lost all of his social life and connections".

Participants also explained how simple, everyday things like going to the shops can become a trigger for grief for people who are recently bereaved "I knew a woman who couldn't face looking at the Lurpak because that is what her husband liked – simple things become so difficult".

Participants also highlighted how it can be difficult to re-establish relationships once a person's caring responsibilities end, as a carer may have lost their social skills and confidence.

Another really important facet of bereavement that the participants raised was that, quite simply, death and dying are difficult subjects to discuss. People do not know how to talk about bereavement: "[after the death of my partner] my neighbours hide away from me because they do not know what to say to me anymore". The research also revealed the lack of planning around death and dying and how end of life planning was discussed at the very last stages, by which time not many options were available and not much could be done. Carers highlighted that "conversations with

patients should happen when they are healthy enough to have them – people should be able to plan and know what they want from palliative care". From a carer's perspective, participants noted that "carers often cannot access the support they need including anticipatory grief planning; this means that their loneliness and social isolation is more likely to become chronic after bereavement".

The difficulty and awkwardness of talking about death and bereavement was shared amongst people from all different cultures, socio-economic background and ages that took part in the research.

#### Socio-economic factors

"Low income and inequality need to be tackled. It is an underlying cause of a great many social ills – food poverty, fuel poverty, poor housing – when you cannot even afford your basic needs how will you meet your social needs?"

People's socio-economic conditions can have adverse consequences for their quality of life, their ability to meet their basic needs and to have and maintain social contacts and interactions.

"Having a low income affects your quality of life – your quality of life is completely diminished. You cannot even afford your bus fare to even go to the park – you feel completely isolated – you are stuck in the house".

"Isolation and loneliness is a threat to your life, you are stuck in the house, a cold house, it's damp and you can't afford to heat it – with the winter we have had – a lot of people have suffered".

"If you are on a low income then you cannot afford a lot of social interaction that is available in our societies – you cannot go out for drinks, go for dinner or even pay for the cinema"

Participants also related socio-economic background with access to information: "Middle and upper socio-economic classes are better equipped to know where to find information about services and activities as they have more media available to them, they have access to a computer, internet and the skills of how to use them".

Having access to fewer financial resources also meant that people lost confidence in enquiring about activities and services for fear of it being unaffordable, this perpetuated a range of perceived cost barriers. "I don't think I can afford to get involved in things, whereas there might not be any cost involved – but I am scared to inquire because I might not be able to afford it".

Carers and those with long term illnesses spoke about the financial constraints they faced and how the benefits system was not able to support them appropriately or take into consideration their needs. "Carers living in economic deprivation who become bereaved often cannot afford funerals. Once they have become bereaved their economic support [benefits] is cut off straight away meaning they no longer have access to carers' benefits or ESA [Employment Support Allowance], which oftentimes means that they are immediately deemed fit for work. This puts undue

pressure on people as there is uncertainty if they will be able to keep their houses or pay their bills".

"If you fall ill or are terminally ill you may have to leave work and keeping up with your bills and basic needs can be difficult".

Many people who are in work find it hard to navigate the benefits system and do not know what benefits or support they are entitled to; there is so much complexity and confusion<sup>16</sup>. Participants spoke about the benefits system and how "you don't know what benefits are out there", the "stigma in enquiring about benefits", and "inconsistent information regarding benefits". There was also fear of sanctions – with participants saying they were "afraid to volunteer in case of being sanctioned". Although there is guidance produced by the Department for Work and Pensions on volunteering and benefits<sup>17</sup>, none of the participants we spoke to were aware of the rules that applied.

Not being able to work or volunteer restricts your social contact and can lead to chronic loneliness and social isolation. "When you are working you have daily interactions with peers and build a social network whereas if you are unemployed you are unable to do this".

Employment was also raised in the context of insecure employment contracts such as zero hour contracts and the impact that this has on that person's living conditions. Participants spoke about the rising levels of in-work poverty where families with at least one member in employment are still having to resort to using foodbanks and the negative implications this has for people's mental health, physical health, wellbeing, and for loneliness and social isolation.

It is worth highlighting that the research participants acknowledged that loneliness and social isolation could be experienced by people from all socio-economic backgrounds, but that it was often more pronounced or difficult to overcome for people from less affluent backgrounds.

### Alcohol and drug dependency

People identified the link between loneliness and alcohol abuse: "If you are lonely you can start abusing alcohol and drink – because it gives you something in your life, even if that is an excuse to go to buy it – a walk to the shop."

The ubiquity of alcohol, tobacco and unhealthy food outlets within areas of deprivation was also seen as a reason for the high rate of dependency and addiction. Recent research shows that there are 40% more places to buy alcohol in the most deprived neighbourhoods<sup>18</sup>, and people with the lowest incomes are most affected by high concentrations of alcohol outlets in their neighbourhood<sup>19</sup>.

<sup>17</sup> Department for Work and Pensions. (2017). Volunteering and DWP Welfare Benefits

<sup>&</sup>lt;sup>16</sup> Feeding Britain. (2018).

<sup>&</sup>lt;sup>18</sup> Alcohol Focus Scotland. (2018). Alcohol Outlet Availability and Harm in Scotland

<sup>&</sup>lt;sup>19</sup> Shortt, NK., Rind, E., Pearce, J., et al. (2018). Alcohol Risk Environments, Vulnerability, and Social Inequalities in Alcohol Consumption, Annals of the American Association of Geographers, 108:5, 1210-1227

Participants also noted that there were re-occurring instances of loneliness and social isolation amongst older people which can lead to alcohol and drug abuse. This chimes with the findings of the *Drink Wise Age Well* initiative whose research into use of alcohol amongst over 50 year olds has found that the 'most frequently reported reasons for drinking more included retirement, bereavement, loss of purpose, less opportunities to socialise, and change in financial circumstances'<sup>20</sup>, which are also commonly recognised triggers for loneliness and social isolation.

#### Social anxiety

Research respondents highlighted the relationship between social anxiety and loneliness and social isolation. Participants noted that "people who are extremely lonely experience anxiety".

Participants raised the point "anxiety really impacts on your confidence", and the negative impact that can have on people's social skills. Research has shown that a lack of social contact can have a detrimental effect on social skills. Professor Sabina Brennan, highlights the knock-on effect of loneliness and social isolation being reduced social skills. She describes loneliness as a causal factor for depleted social skills in an individual as opposed to the misconception that people who have poor social skills are those who become lonely<sup>21</sup>. The views of research participants also chimed with this, "like every other skill – if they [social skills] are not practiced you begin to lose them".

We learnt from our respondents that social anxiety was a reoccurring issue on social media and that people from across different generations were using platforms such as Instagram and Facebook to discuss their experiences. There was a sense amongst the participants that social media was a source of both good and bad – it could provide people with a platform to express their emotions and connect with others as well as deter people from making real connections. The need for constant and immediate gratification in the form of 'likes, views and shares', was also raised as an underlying factor in the relationship between anxiety, loneliness and isolation.

Loneliness has often been defined as the gap between our actual and desired social relationships<sup>22</sup>. Participants described the effects of so called 'aspirational lifestyles' which are publicised on social media, and how this impacts on people's own sense of self-worth and the value of the relationships they have and causes a heightened fear of social rejection.

It is worth noting that research participants felt that this was experienced by people of all ages and socio-economic backgrounds and was not limited to, as is thought, the younger generations and less affluent.

# Lack of support from health services and General Practitioners

One of the most important issues highlighted was that healthcare professionals do not always recognise or acknowledge loneliness and social isolation. Participants

<sup>&</sup>lt;sup>20</sup> Drink Wise Age Well. Why is alcohol and ageing an issue?

<sup>&</sup>lt;sup>21</sup> Loneliness in Scotland Summit. (2016). Befriending Networks.

<sup>&</sup>lt;sup>22</sup> Scharf, T. (2016). Responding to loneliness: opportunities and pitfalls. Voluntary Health Scotland

also raised the issue of the lack of parity between mental and physical health. Participants understood the time pressures that General Practitioners were under, and realised that this was an underlying cause of the lack of recognition and compassion that the healthcare service could offer.

"Healthcare continuum needs to better understand how to recognise loneliness and social isolation and provide the support that is needed". "District nurses and healthcare staff in general need to be given training on how to recognise loneliness and social isolation".

Respondents emphasised the lack of support for non-physical conditions such as loneliness and social isolation and depression from healthcare services. "I know many people who have been to their doctor's with physical problems underlying which are loneliness and mental health issues but the GP has a 10 minute slot and a lot to fit in. So it becomes a case of we don't have time to discuss all of this today so we will make you another appointment in 4 weeks. Sometimes you are given a number for self-referral — and it feels like the doctor has taken it out of their own hands and made it your own responsibility. If you are depressed and lonely how can you go and phone that number or use a service — you will end up going back to that empty house and the same circumstances".

"NHS staff and GPs are far too busy, they have 10 minutes to deal with you and they are looking for a physical issue".

The Chief Medical Officer for Scotland has put a lot of emphasis on compassionate health and care services, and the Royal College of Physicians of Edinburgh in their conference *A Patient's Tale*, defined compassion as: 'recognising pain, distress or suffering and taking action to address or relieve it'<sup>23</sup>. The conference emphasised that compassion involves taking positive action to prevent, ameliorate or remove a person's problem or distress. It is important that health, social care and other public services do more to understand the nature and importance of compassion, in order to improve service users' experiences of services.

The participants offered examples of when they had received compassionate health care and how transformative that was for them, "My gynaecologist picked up on my loneliness and social isolation. The only one to ask me "tell me about yourself", she looked at me as a person and actively listened and recognised the issue".

People spoke about the need for healthcare that is holistic and caters to both mental and physical health. "Services are not joined up – it is very hard for someone who is suffering from loneliness and mental health issues to get continuity of healthcare that is holistic. For example, when you go to a GP they may prescribe some medicine but you very rarely receive a social prescription and link workers are few and far between".

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<sup>&</sup>lt;sup>23</sup> Royal College of Physicians of Edinburgh. (2017). A patient's tale: how compassionate is our NHS?

There was a strong call from the participants for healthcare services to focus on prevention and early intervention. "NHS has to shift from being about fixing people to being about preventing people from becoming broken".

Carers also spoke about their changing circumstances and the lack of support at different stages of their caring journey.

"The gap between a person's diagnosis and death is widening and there need to be more services to help both the patient and carer during this in-between period."

"Carer's assessments, if they are carried out, are a one-off but your needs change as the condition of the person you are caring for changes. Patients' needs change physically and emotionally and the carer's assessment needs to be done again."

#### Loss of identity

Participants discussed the concept of losing your identity and the correlation with loneliness and social isolation. Participants noted that "People, due to a number of reasons—becoming a student, retirement, parenthood, migration, bereavement, illness, change of relationships—can lose their identity and sense of self. This can trigger loneliness, which makes people introspective... you lose yourself even more". It is interesting to note that many of the 'reasons' noted for losing your identity are also triggers for loneliness and social isolation. Explanations of why the two were related included, "not [being] understood or if you do not fit in [after your circumstances change] you can become really lonely and isolated—this can lead to your confidence being diminished and can cause you to become quite vulnerable".

Some participants highlighted the self-inflicted nature of the isolation. "Stigma related to a physical or mental health condition, or a change in your socio-economic condition can lead many people to make a personal choice to isolate themselves – they don't want to be labelled or pitied so they withdraw into themselves".

Participants from Marie Curie included a range of professionals and also members of a carers' group raised a number of important issues that carers, both paid and unpaid, and those living with terminal illness face.

"If you have a terminal illness – the disease is in control of everything and your loss of control can eat away at who you are".

"Ability to care and be cared for is complex. Not only are people dealing with their own bodies changing, their illness and physical condition, but also the encroaching impact of these on their mental health and wellbeing".

The loss of identity amongst those with caring responsibilities came out strongly in the focus groups and a poster in the halls of a Marie Curie hospice illustrated the harrowing situation that carers can find themselves in. The poster showed a carer describing themselves as "no-one".

The poster acted as a self-identified stimulus for a group of Marie Curie staff who claimed that "Caring permeates [people's lives] and defines [them]".

Carers can feel redundant in their family roles and statements such as "*I am not a wife anymore because I am caring*" were common and shared amongst many people in various family relationship and caring roles.

#### **Carers**

The concept of losing your identity, losing what it means to be you, the things that you enjoy doing and who you are in relation to those around you, was never more evident than it was for carers.

Carers and their representatives also spoke about "[The] constant guilt for wanting some time for yourself" or the need to "always put the person they are caring for first, there is no time to do even the simple things like wash and eat properly at times".

Participants also highlighted the "longevity of the burden of being a carer for people with neurological conditions as opposed to caring for someone with cancer." Carers supporting people with long term conditions cannot get any regular support or respite as other people with immediately life limiting conditions are often a priority and this leaves carers isolated with diminishing social contact over a long period of time.

When we realise this alongside the wider context within which carers exist we realise that carers do not get the support that they require. "Employers are not supportive or understanding of caring responsibilities – they often don't recognise caring and do not offer flexible solutions – when you have a child you get maternity leave - why not something similar for carers?".

"Sometimes you can be a carer for 20 or 30 years – you can't afford to not work." This not only adds financial constraints but also limits social contact and can have a debilitating impact on people's self-worth, if they can only fulfil the role of a carer and are not able to achieve the other things that what they want in life, including their career.

"Sometimes GPs don't even know that their patient is a carer – this further removes carers from support". Participants described how it was difficult for GPs to understand the stresses and issues they were going through as they frequently did not know their patients were carers. This also meant that GPs were unable to provide adequate support or signpost to suitable services as they were often simply looking for a physical health issue.

"There is a lack of services to support carers with the normal stuff, let alone respite". This lack of services and support can also continue after the caring responsibility has ceased impacting on people's sense of loneliness and isolation. For example, "services such as community nurses, start to be withdrawn after the person being cared for dies, the sudden removal of these services can leave bereaved people feeling extremely isolated and alone<sup>24</sup>".

<sup>&</sup>lt;sup>24</sup> Marie Curie. (2018). Building a Connected Scotland: Tackling Social Isolation and Loneliness Together

#### **Children and Young People**

Children and young people were a group that were recognised as potentially also suffering from loneliness and isolation, mainly in the form of bullying and segregation within schools.

A recent BBC Survey, The Anatomy of Loneliness, has revealed that '40% of 16 to 24-year-olds who took part [in the research said] they often or very often feel lonely, compared with 27% of over 75s<sup>25</sup>.' The survey also explores some of the reasons why 16-24 year olds reported the highest levels of loneliness in their study. Some of the reasons included; young people having a lack of experience of loneliness, its intensity and duration as well as 16-24 being the age when identity is changing. In our own research participants highlighted the impact changing and transitioning identity can have on people's sense of belonging and connection to others. They noted trigger periods for loneliness and social isolation such as leaving school, entering higher education and moving as being particularly difficult especially in formative teenage years and early adulthood.

Participants emphasised the role of the education system and the need for a focus on developing and acknowledging soft skills, building resilience and shifting the attention away from accumulating a lot of information towards exploratory learning and trying to problem solve and figure things out for yourself.

The charity Children's Health Scotland has articulated the social isolation, loneliness and social exclusion that children and young people with long term conditions or life limiting conditions frequently experience<sup>26</sup>.

These children and young people feel excluded and stigmatised if they are not supported and enabled to participate in the same activities as their peers at school and out with school. They may suffer from mental health issues, depression and poor body image. After diagnosis many parents report their children become reclusive, having previously been outgoing and happy. "It becomes a habit. It becomes normal to be lonely".

Absence from school due to treatment or hospitalisation sees children fall behind in their education, lose touch with classmates and become anxious about returning, causing further isolation. If they are beyond school age and not in work, training or education their isolation continues, and their situation can be exacerbated by other characteristics such as sexuality or ethnic background, resulting in increased stigma.

This can have a lifelong impact: if children and young people can't make social connections and learn social skills during adolescence it is more difficult for them to do so in later life.

#### A lack of open and neutral spaces

"Stuck at home" was a reoccurring phrase when discussing loneliness and social isolation – participants always came back to this central idea that you have nowhere

<sup>&</sup>lt;sup>25</sup> BBC. (2018) The Anatomy of Loneliness

<sup>&</sup>lt;sup>26</sup> Voluntary Health Scotland. (2016). VHS Conference Key Messages: Loneliness A Threat to Health

to go except your home. Sometimes these homes were described as sanctuaries where people could hide and other times they were seen as inadequate and people used words like "trapped" to describe how they felt about not being able to get out.

Many participants highlighted the negative impacts of inadequate "places to be" these included "cold and damp homes", unsafe neighbourhoods, lack of community spaces, expensive local activities and the lack of usable outdoor spaces including benches and parks.

They emphasised the role of places where social contact could be made and where networks and community could be developed. They noted that places included everything from your home, to the streets and your neighbourhood, your local parks and the shops you enjoyed visiting as well as the infrastructure that helped you access these places. The latter included transport but also the projects and activities available within the spaces.

#### **Transport**

A lack of appropriate and affordable transport can cause people to become isolated and lonely.

"Some of our volunteers get public transport to our volunteering group but there have been times when volunteers have struggled to afford the weekly bus fare to come out – this stops people from getting involved".

"We hear this all the time: 'I like to get out' but because of people's socio-economic conditions they may not have money to take driving lessons or use public transport – so they can't get out as much as they like – further isolating them".

"You are stuck at home with only the TV to keep you company – because you can't afford or there isn't any suitable transport...this is a big factor in leading to depression and the other things that follow depression"

Participants noted that rural communities often rely more on public transport services – "this [transport] is a hot topic in many community council meetings – bus services being cut or routes changed. It is an important factor in people being able to get out and about for groceries or out to meet people and do things"

"If you don't drive" you are reliant on public transport which can be expensive and unreliable.

Installation of cycle routes and walkable paths and spaces help provide a solution: "I know an area where a cycle route has just recently been installed. Before, you had to walk or cycle down a dirt path next to a main road where national speed limits apply. People between those two towns, which are such a short distance from each other, would be completely isolated if they did not have a car or could not afford public transport".

Participants found the process of applying for a bus pass difficult and many of the participants we spoke to who would be eligible for a free bus pass either did not know about their eligibility or did not know how to apply or where to get more information on how to apply.

These larger scale infrastructure issues naturally link the person and subjective (loneliness) with the environmental and object (social isolation), and therefore link to power and actionable policy recommendations at the broadest level. In order for transport routes, availability and pricing to reflect the needs of the population who will utilise it, transport decisions need to be taken locally.

#### **Black and Minority Ethnic Communities and New Scots**

The life stages, issues and triggers for loneliness and social isolation identified in this report are shared between BAME and non-BAME participants. The propensity of migrant and minority ethnic groups to become lonely and socially isolated relates in part to the concentration of risk factors that affect socioeconomically disadvantaged sections of society more generally, which include poverty, poor housing and unemployment, etc.<sup>27</sup> Research shows that at a neighbourhood level, minority ethnic people and migrants are more likely to reside in areas characterised by high unemployment, poverty and poor quality public spaces<sup>28</sup>.

The BAME women involved in the research highlighted how their situations were often exacerbated by socio-economic disadvantage from not normally being able to work and often being economically dependent on a spouse or children, lack of access to knowledge and information, the existing health inequalities they experienced as a result of these socio-economic disadvantages and cultural alienation<sup>29</sup> from their original and host countries<sup>30</sup>.

Some participants added that in order to preserve a sense of identity they had held onto ideas and practices from their original cultures that had "become outdated even in those countries" making it harder for them to integrate into both the host and the original cultures. These ideas often related to gender roles leaving men confined to a work space and women to the realm of the home. This has resulted in further complexity around the triggers for loneliness and social isolation, for example, "what are men supposed to do after retirement", "what is a women's role after bereavement, when her children leave home", and the interplay between these. This also affects the activities and services that they can access to relieve loneliness and social isolation.

The BAME women further noted that services and activities needed to be sensitive to different cultural needs and that connecting with people in a way that they would understand would help break some of the barriers they faced. Support "needs to be driven by what people want – you cannot do things to people or make choices for people – this needs to be developed alongside the people that will use them and all voices need to be supported and listened to."

<sup>&</sup>lt;sup>27</sup> Platt, L. (2007) Poverty and ethnicity in the UK. Policy Press, Bristol, UK

<sup>&</sup>lt;sup>28</sup> Lakey, J. (1997) 'Neighbourhoods and Housing'. London: Policy Studies Institute, pp.184-223

<sup>&</sup>lt;sup>29</sup> Campaign to End Loneliness. (2014). Loneliness and older people from BME groups: challenging misconceptions and stereotypes

<sup>&</sup>lt;sup>30</sup> For those born overseas, cultural barriers can arise from both sides: they may feel disconnected from their country of birth, but not comfortable in the British culture their children were born into.

# **SECTION 2 - Places Spaces and Local Knowledge**

Having defined loneliness and social isolation its connection with mental health, inequalities and power as well as explaining the range of life stages, issues and triggers the aim of this section is to discuss the place based approaches that participants felt nurtured connectedness. Places and spaces were identified by participants as being central to tackling loneliness and social isolation as they encompass both the physical environment (where social contact happens) such as housing, streets, public areas, natural spaces and the mobility of people across these as well as the social environment that is the relationships, social contact and support networks that exist within a community and which support a sense of belonging. Participants also expressed how the social environment can be affected by the quality of physical environment.

This section will look at the importance of place for people's health and wellbeing and the role of places in creating a sense of belonging, giving people a sense of purpose and creating more connected communities' and in doing so reducing loneliness and social isolation. This section will discuss the role of housing, civic spaces and activity, community development and empowerment, the importance of local knowledge, Placemaking and transport, specifically, as having a strong influence on the level of social connectedness within a community.

"Given that culture manifestly exists, it must exist somewhere, and it exists more concretely and completely in places than in minds or signs". Edward S. Casey<sup>31</sup>

How do we create spaces and place with a culture of connectedness, community and inclusion?

#### **Health and Place**

Place is the combined social, economic, physical, cultural and historical characteristics of a location<sup>32</sup>. The health experience of an individual depends on the social and physical environment in which they exist<sup>33</sup>.

Inequalities in the physical environment can create serious disadvantages for people living in deprived areas. In the most deprived areas of Scotland, men experience 23.8 fewer years of good health and women experience 22.6 fewer years compared to the most affluent areas<sup>34</sup>. The ubiquity of alcohol, tobacco and unhealthy foods, the lack of access to affordable fresh produce, green spaces and active travel infrastructure experienced by many Scottish communities render healthy lifestyles extremely difficult, at a great cost to the NHS and the wider society<sup>35</sup>.

<sup>32</sup> Scottish Government. (2012). Good Places Better Health for Scotland's Children.

<sup>31</sup> Senses of Place, 1996

<sup>&</sup>lt;sup>33</sup> Curtis, S., Jones, I.R. (2008). Is there place for geography in the analysis of health inequality? Sociology of Health and Illness, 20(5), 645-672

<sup>&</sup>lt;sup>34</sup> NHS Health Scotland (2016) Health inequalities - what are they and how do we reduce them? Inequality Briefing.

<sup>&</sup>lt;sup>35</sup> McNamee, P., Neilson, A., et al. (2017). A review of the evidence base for modelling the costs of overweight, obesity and diet-related illness for Scotland. University of Aberdeen

The physical environment can also contribute to inequalities in mental health outcomes and suicide<sup>36</sup>: Suicide rates in Scotland's least affluent areas are around three times higher than the most affluent<sup>37</sup>. Evidence demonstrates that specific factors related to the link between area-level deprivation and suicide include: physical (e.g. poor housing conditions); economic (e.g. lack of job opportunities) and infrastructure (e.g. poor quality, accessibility, acceptability of services)<sup>38</sup>. Less affluent areas are far more likely to have these issues.

The built environment spans a number of major policy areas including, transport, planning, housing and public health. By ensuring that people are able to experience the benefits of living in a well-designed, adequately resourced and well-connected neighbourhood, population level health benefits can be accrued<sup>39</sup>.

# Housing

At a basic level place contains our homes and the communities in which we live. On average people spend around 90% of their time indoors and a large proportion of this is within their homes<sup>40</sup>. There needs to be an appropriate housing supply to meet the needs of the population.

Good housing encompasses not only the physical home but also the household circumstances, neighbourhood conditions, and the community in which the homes are set, all of which are an essential pre-requisite for people's health<sup>41</sup>.

With regards to the impact that housing can have on people and their experiences of loneliness and social isolation, our respondents noted that there is a two-way relationship where you can be lonely and isolated and therefore confined to your home and you can become isolated and lonely because you are unable to use your home as a social space. Underpinning both of these scenarios are people's socio-economic circumstances and power to affect change. Participants explained that you are often "stuck in the house" because you do not have the resources to access transport, access social venues, do not feel safe in your area or in fact lack social capital and your social capital is further reduced as you are unable to invite people to your home as it can be "cold, damp and you might not even have money for tea and biscuits let alone having anyone over for dinner". "Not having resources to get out and about"... "Can't afford to go for drinks, go to the cinema"... "Can't even afford your bus fare to go to the park"

Becoming confined to a home that is inadequate for your health can further compound loneliness and social isolation. Participants expressed some of the harsh circumstances people have to live in, "A lot of families have struggled with only being able to afford to heat one room in their house" and "isolation and loneliness is a

<sup>&</sup>lt;sup>36</sup> Webb, RT., Kontopantelis, E., Doran, T., et al. (2012). Suicide risk in primary care patients with major physical diseases: A case-control study. Arch Gen Psychiatry 69(3): 256-264.

<sup>&</sup>lt;sup>37</sup> ScotPHO (2018). Suicide: Key Points.

<sup>&</sup>lt;sup>38</sup> Samaritans. (2017). Dying from Inequality.

<sup>&</sup>lt;sup>39</sup> The Built Environment and Health: an evidence review

<sup>&</sup>lt;sup>40</sup>Glasgow Centre for Population Health. (2013). Concepts Series 11 – The built environment and health: an evidence review.

<sup>&</sup>lt;sup>41</sup> Tweed, E. (2017). Foundations for well-being: reconnecting public health and housing. SCOTPHN.

threat to your life, you are in a cold house, its damp, you can't heat your house – the winter we have had, a lot of people have struggled".

Many aspects of housing directly influence health; for example, insulation quality and lung health, physical condition of housing and risk of injuries, homes lacking basic equipment such as cookers, fridges and freezers affecting malnutrition and obesity and health issues resulting from fuel poverty. There are also a number of underlying factors that connect housing to health, these include:

- Financial circumstances
- Housing satisfaction
- Education and employment
- Access to health and care services
- Health behaviours
- Empowerment and control
- Environmental sustainability
- Relationships and social capital<sup>42</sup>

Participants highlighted the lack of affordable housing (both owner occupied and privately rented) and the effect this has on community cohesion within local areas. The lack of community ties in such situations further diminish the sense of place and belonging. They suggested a need for more social housing and well-designed affordable homes that are appropriately equipped and tailored to cater to the needs of an ageing demographic.

Participants also suggested the development of a "mixed housing stock, so that accessible one bedroom homes were in the same apartment blocks or areas as large family homes". This would promote more intergenerational support and would provide diverse communities with the opportunities to mix and integrate with one another, organically. These types of homes and communities could also help to preserve family and friend support networks. They also suggested that affordable and social housing should be fully integrated and indistinguishable from private housing. It was important that "people who were living in social housing should not be made to feel stigmatised or segregated within their communities".

The research has identified that features of place and community such as access to services and amenities safety, transport and connectedness as well as opportunities for recreation and socialisation are important contributing factors to people's health and wellbeing and impact greatly on people's experiences of loneliness and social isolation.

#### **Civic Spaces**

A breakdown in people's social capital due to a number of societal changes has resulted in an increase in loneliness and social isolation. The fragmentation of society due to suburbanisation<sup>43</sup>, socio-spatial fragmentation within cities, the growth

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<sup>&</sup>lt;sup>42</sup> Ibid, pg13

<sup>&</sup>lt;sup>43</sup> Also referred to as the urban sprawl

of the nuclear family and single person households<sup>44</sup> and an overall ageing demographic has meant that there is now a greater need for innovative public spaces to bring people together, to develop trust, understanding and deeper social connections.

What constitutes a public space? Are they high streets, local markets, parks and allotments? Do they include privately owned public spaces such as shopping centres, art galleries or even car boot sales? What about quasi-public spaces or micro-spaces such as station forecourts, stairwells, street corners and school gates? According to research conducted by the Joseph Rowntree Foundation in 'The Social Value of Public Spaces', "more successful social spaces… were [those] that encouraged people to play a vital role in the evolution of activities that helped shape those places"<sup>45</sup>; as such they are often civic spaces and can encompass a range of public spaces.

Civic spaces are an extension of community and can form the setting for celebrations, social and economic exchanges, and a place for friends and cultures to mix and can contribute to community health socially, economically, culturally and environmentally<sup>46</sup>. Civic spaces have a great role to play in tackling loneliness and social isolation; creating nurturing and open places which people can come to and use on their own terms.

All of the participants noted the importance of having "places to be". Projects and services have a positive impact on creating community cohesion but it was equally necessary to have places without any agendas that people could access on their own terms.

Defining what is meant by an agenda is inherently complex and is indicative of how difficult it is to try understand what a place without any agendas would look like. Research participants grappled with the concept of an agenda-less place and came to the conclusion that an agenda could be defined as a label, for example, "an arts group for 16-24 year olds" or "a community bus for the elderly". The types of spaces that have an agenda were defined by the participants as having strict formal or informal (in the sense of cliques) joining and access requirements, often catered to a set demographic and were often the venue where formal services and projects were delivered.

When probed as to the types of places and spaces they would like to see participants noted a range of neutral and mixed use spaces. They highlighted a need for better resourced and rebranded community centres, open library spaces or hubs with adapted social areas, safe local parks and other usable greenspaces, as well as affordable gyms, affordable cafes, community kitchens and places where people can connect over food and music. These, participants felt, were key to resolving loneliness and social isolation but they also noted the importance of a bench to sit

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<sup>&</sup>lt;sup>44</sup> In Scotland, the number of single person households is increasing, and this is estimated to grow. <u>Scotland's 2011 census</u> shows that single person households are the most common household type, accounting for 35% of all households and this is expected to grow to around 41% that is 1.15 million by 2037

<sup>&</sup>lt;sup>45</sup> Worpole, K., Knox, K. (2007). The social value of public spaces. Joseph Rowntree Foundation.

<sup>&</sup>lt;sup>46</sup> Project for Public Spaces. (2009). What is a great civic space?

on, "nice" and "local" high streets, clean and free public amenities such as toilets as well as clean and beautiful streets that would make you want to go outside. Where there are price reductions for accessing places and activities for people on low incomes, participants noted that this could cause embarrassment and stigma for those that would have to disclose their personal circumstances. As such they strongly advocated for the cost of accessing these spaces and activities to be low for all in order to increase inclusiveness and usage more generally.

Participants also wanted "an opportunity to interact with people they would not normally hang around with, for example students, elderly, people with and without jobs, people from other cultures, and people with disabilities". They wanted to be able to mix with different social stratas and reinvigorate a community vibe. Participants emphasised that there is not a single community of interest or demographic that exists in any one community or place but in fact our communities contain a range of complex and distinct demographics and places needed to be designed and correlated in order to bring everyone together, not cater to distinct needs in separate spaces.

There should be a range of well-designed places and spaces that cater to the needs and requirements of the diverse communities that exist. A very illuminating point made by Karen Anderson of Architecture and Design Scotland emphasises the lack of requirements for inclusive and well-designed spaces. 'Design stipulations for vehicles have been explicit for decades: turning circles, corner radiuses, etc. – all are set out and have become increasingly demanding. There are, by contrast, no requirements for accommodating people: e.g. seats, gathering points, play stops, public toilets or trees; no requirements for well-designed connected routes that make walking and places a pleasure<sup>47</sup>.'

According to participants the importance of "open and communal spaces without barriers to access that all people can access" would help form and strengthen social connections. They also highlighted that "lighting, the physical space, emotive colours would encourage positive communication and mood". They also emphasised the power of food and music to bring people together across a range of backgrounds, cultures and socio-economic backgrounds. "Music is quite emotive and means something to everyone…oh I hate this song or this reminds me of my mum".

"A space with an open kitchen was set up locally where people could come and buy lunch or dinner. This gave people an opportunity to come and meet people. Services, activities and support were then set up around this – but people could opt to just have a meal, sit and have a hot drink or participate in what they liked. It was a great idea to combat loneliness and social isolation but it is not working anymore because they have stopped the kitchen and now the services and activities have dropped out".

Participants also raised concerns regarding the tendency of informal spaces to result in the development of cliques which can be exclusionary. However, they emphasised that if the activity or space has a purpose such as it serves food or is a library hub, or

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<sup>&</sup>lt;sup>47</sup> Anderson, K. Blog: How can we use design to help create a caring place? Architecture & Design Scotland

even a supermarket cafe then the primary focus will remain on that. You can still access the space for those reasons even if you do not want to engage in the other activities that are going on.

## What are the main features of successful social spaces?

According to a study of a wide variety of public spaces in Cardiff, Preston and Swindon<sup>48</sup> the following 'rules of engagement' have been suggested to help foster and support shared social spaces:

- access and availability good physical access, welcoming spaces and extended opening hours;
- invitations by peers and others embedded in social networks to encourage use;
- exchange-based relationships moving beyond consumerism to participation in the exchange of goods and services;
- choreography of spaces by discreet good management while also leaving room for self-organisation;
- moving beyond mono-cultures encouraging diverse groups and activities to share common spaces; and
- avoiding over-regulation of design and space, as security and well-being are more likely to grow out of active use<sup>49</sup>.

## **Civic Activity**

In the same way as a space that is without an agenda but with purpose, engaging in civic activity can have a positive impact on people's feelings of loneliness and social isolation.

Participants felt that engaging in activities that focused on a sense of community helped foster strong bonds. In discussion with participants it became clear that those services, projects and activities that work towards a common goal rather than focusing on the individual were seen to have the most positive impact in tackling loneliness and social isolation. Participants said that "they loved being part of a community and having a shared sense of achievement". In other words, support that gives a sense of purpose and provides clear goals. "Every other aspect of people's lives was seen as competitive and there was a need for a supported and inclusive environment where people could do things together."

A predominant theme amongst the participants was that they would either feel uncomfortable or would not take part in activity if it "was about them". In other words, they did not want to be passive recipients of services. These comments were made in reference to services, community groups or activities directly aimed at tackling loneliness and social isolation.

<sup>&</sup>lt;sup>48</sup> Mean, M., Tims, C. (2005) People make places: Growing the public life of cities. Published by Demos.

<sup>&</sup>lt;sup>49</sup> This includes things like signs which forbid skateboarding, playing ball games or even walking on the grass or having a picnic. These spaces act as a deterrent for people to feel comfortable to use the space.

"Many of the volunteers I have worked with would not come along if the activities were about them, even though many of the volunteers may be lonely and some of them would acknowledge that, this is not the reason why they are volunteering. They are here to do something useful, they are coming to volunteer and contribute to their community". This also highlights the importance having a sense of purpose and belonging instils in people's lives and the impact this has on their ability to form social connections and be part of a community.

Participants further added that they wanted to take part in activities that were reciprocal or in which people felt that they were also able to contribute something: "we like to do things and participate in things that are useful and contribute to something – like volunteering".

"Our volunteering opportunities provide an open and accepting environment that is not competitive, everyone's skill sets can make it work on the day".

"Volunteering meets our social needs whilst also giving back to our communities and supporting people around us"

## **Community Empowerment**

NHS Health Scotland note that 'Community empowerment, community engagement and co-production (working with communities to achieve positive outcomes) are essential to improve health and social care outcomes and reduce health inequalities through action on place (actions that improve the places where we spend time)'.<sup>50</sup> The work of Community Planning Partnerships and Integrated Joint Boards to deliver effective provisions needs to be calibrated so that it takes into account the needs of people, especially those in deprived areas.

Participants in our research reflected that many people would need help to access spaces and places designed for their use and that having spaces alone was not enough. As such it can be said that meaningful and relevant community development is a pre-requisite to an empowered community. This includes a range of capacity building activity to ensure "people are upskilled so that they can grow and develop and not become reliant on a project or service".

"Places are important but not on their own, need to do something with the spaces that involves people and encourages them. Otherwise what tends to happen is that those people who are not socially isolated or lonely, who don't have barriers to access or communication, end up with a great space. It is letting really vulnerable people fall through the gaps — it doesn't solve the problem of loneliness and social isolation as those people are still at home feeling lonely and isolated".

Research participants noted that they wanted support to develop their skills and confidence and in doing so build and develop individual and community capacity, rather than have a continued reliance on services. They also highlighted the importance of "user-led activities" and services and projects take on an "asset-based"

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<sup>&</sup>lt;sup>50</sup> NHS Health Scotland. (2016). Place and Communities

approach and facilitate service users to develop projects and activities in their own local communities as they are required".

Participants noted that the community development projects that do exist tend to focus on a specific project or intervention instead of the community as a whole. Scottish Community Development Centre feel that community development itself is often seen mainly as support for community projects rather than an approach whereby communities work together to engage in collective action. This can mitigate the effects of inequality but will not tackle them in the same way as collective action in communities might<sup>51</sup>. A great example of successful civically minded activity is the Govanhill Baths where people from all backgrounds rallied together against the closure of the Govanhill Baths, which has resulted in the re-opening of the Baths and also the transformation of the venue into a community hub<sup>52</sup>. The facilities, projects and activities are led by the communities that use them and they have re-opened the Baths as a wellbeing centre as well as hosting a range of programmes that contribute to the wider social, cultural and built regeneration of Govanhill as a community. This type of mixed use space increases the potential for people of a diverse range of cultures and backgrounds to come together through chance encounters.

# **Signage and Local Information**

Joseph Rowntree Foundation have pointed out that 'poor signposting inadvertently suggests that there is little of interest in and around town centres other than shopping, and many interesting local features and historic assets often go unnoticed and unvisited'<sup>53</sup>.

A lack of local knowledge and local information was a reoccurring theme: participants did not know what local resources existed, and if they did they did not know how to access them or whether or not there was a cost attached. Most participants perceived even free services would have some sort of costs attached that they may not be able to afford. Participants highlighted that this could add another barrier for people on low incomes to engage with activities within their own communities. They also highlighted that people with more disposable income had access to more media and forms of information so they could find out about whether they wanted to get involved in and enquire about costs online without having the stigma of not being able to pay for it.

It is important to match what people need with what is available locally, whether that is a statutory, private, independent or third sector service or opportunity. ALISS (A Local Information System for Scotland) is consistently promoted to the NHS as a signposting resource. However, several participants in our research were of the view that ALISS is difficult to navigate and/or use and that information on ALISS is limited and/or out-of-date. They did not consider it an adequate resource to meet the needs of people suffering from loneliness and social isolation or indeed the needs of

<sup>&</sup>lt;sup>51</sup> Voluntary Health Scotland. (2017) Kiren's Blog: The Spirit of Kinder Communities

<sup>52</sup> http://www.govanhillbaths.com/

<sup>&</sup>lt;sup>53</sup> Worpole, K., Knox, K. (2007). The social value of public spaces. Joseph Rowntree Foundation.

service providers or health professionals looking to signpost. The demand for a tool that can list the range of activities, services and groups within a specified area in an up-to-date, clear and consistent manner, was very evident from our research.

Participants thought it was important to have "signage, leaflets about the local area with information about where you can go and how you can use spaces and what people can expect. People fear the unknown".

Participants' lack of awareness about resources extended to knowledge of local parks and greenspaces, library groups and community groups. An example given was Gartnavel Hospital which was recognised as having wonderful greenspaces but which we were told are very under-used.

"We had a situation where a woman came to us wanting to know about playparks and greenspace in her local area. Her daughter loved being outdoors and so they would quite often get in their car and drive to a play park, play for a bit then drive to another park – sometimes they would drive to five or more parks in a day. However, it turned out she lived a two minute walk away from a well maintained woodlands area, she knew that it existed but did not know how to use it. She did not know if it was open to the public and how to get in, she also thought that there would be too many paths and she would get lost."

Participant said that it was really important to make sure that greenspaces are well maintained and clearly signposted as this makes them more accessible. There should be readily available information about walks, paths and greenspaces in all areas, in a range of languages and accessible formats.

Poor or negative local information also has a role to play in fuelling resentment and negative attitudes towards people's own local areas. It has also resulted in what is deemed "the reputation effect", whereby areas or places gain a poor reputation for safety, amenities and services and it is then difficult to reclaim a good reputation<sup>54</sup>. Participants highlighted the importance of local knowledge in changing perceptions: "My space is special, knowing the history of your own spaces can mean that your perception of it changes too".

A great example of local information changing perceptions is a booklet, 'North Edinburgh's Hidden Gems', detailing local walks, developed by Pilton Community Health Initiative (PCHI) for their local community<sup>55</sup>. North Edinburgh is 4 miles from the city centre of Edinburgh. The booklet offers people living in some of the most deprived areas in the North of Edinburgh a sense of pride in their community by providing a range of information on sights and places of interest as well as giving practical information on estimated walk times and accessibility of routes.

<sup>&</sup>lt;sup>54</sup> Worpole, K., Knox, K. (2007). The social value of public spaces. Joseph Rowntree Foundation.

<sup>&</sup>lt;sup>55</sup> Pilton Community Health Project. North Edinburgh's Hidden Gems.

# **Placemaking**

Place, as the environment that surrounds us, has a substantial influence on our health. It can create and nurture health but it can also be detrimental to health<sup>56</sup>. Access to local facilities, services and amenities has been associated with positive health outcomes and whilst socio-economic disadvantage does not directly correlate with access to fewer services and amenities, it is in fact the quality of services on offer that can have a health enhancing or damaging effect. The ubiquity of alcohol, tobacco, gambling and fast food outlets in socio-economically deprived areas and the lack of access to affordable fresh produce, green spaces and active travel infrastructure<sup>57</sup> render healthy lifestyles extremely difficult, at a great cost to the NHS and the wider society.

Spaces need to be designed to encourage activity, connectivity and a sense of community ownership. Proximity to an adequate quantity of high-quality greenspace has been found to have a protective effect on health<sup>58</sup>, with its availability in areas of social deprivation potentially reducing health inequalities. People are more likely to use greenspace if they think it is safe, well-maintained and easy to reach<sup>59</sup>. Those living in areas of the greatest socio-economic deprivation are less likely to live within walking distance of greenspace and less likely to be satisfied with that greenspace<sup>60</sup>. The fact there is a lack of availability of good quality parks, recreation and sports facilities in areas of socio-economic disadvantage, further exacerbates health inequalities and can cause or intensify feelings of loneliness and social isolation as there are fewer chances to meet people opportunistically. Participants noted that activities involving greenspaces as well as the spaces themselves have a lot to offer in terms of people's own sense of wellbeing, but also, engaging in developing and maintaining greenspaces can help people work together and develop strong bonds often at a very low cost.

It is important to value streets as places. Maintaining streets is said to have a positive effect on neighbourhood satisfaction, perceptions of safety as well as neighbourliness and social connections within a community. Poor maintenance of streets can create negative perceptions of a place, damage community resilience and discourage people from investing in their homes and communities<sup>61</sup>. It is also important to highlight that the maintenance of public spaces in areas of socioeconomic disadvantage is often poorer in comparison to more affluent areas<sup>62</sup>.

Conversations with participants highlighted that people often do not feel connected with the areas outside their own home, their local streets or parks. Participants

<sup>&</sup>lt;sup>56</sup> Glasgow Centre for Population Health. (2013). Concepts Series 11 – The built environment and health: an evidence review.

<sup>&</sup>lt;sup>57</sup> Ibid

<sup>&</sup>lt;sup>58</sup> Groenewegen PP, Van den Berg AE, et al. (2012). Is a green residential environment better for health? If so, why? Annals of the Association of American Geographers; 102(5):996-1003.

<sup>&</sup>lt;sup>59</sup> Balfour R, Allen J. (2014) Local Action on Health Inequalities: Improving Access to Green Spaces. Health Equity Evidence Review 8.

<sup>&</sup>lt;sup>60</sup> NHS Health Scotland (2016). Place and Communities

<sup>61</sup> Ibid

<sup>&</sup>lt;sup>62</sup> Scottish Government. (2012). Good Places Better Health for Scotland's Children

stressed that this perpetuates the idea that these areas are not their responsibility but also that they do not actually belong, and as such these areas are left unused. Participants highlighted the "need to get out to clean the streets and the gardens and take pride in the local area" and many gave anecdotes of people within their own community or elsewhere who had taken the initiative to do this. The result of some people taking the initiative to clean up their local areas caused others to "want to take part and share the responsibility... soon we all got to know people we never even spoke to because they were out and about in their garden or out for a walk". The fact that people were using the outdoor space around them created more opportunities for people to interact and also had a positive impact on community safety, with "people looking out for each other". Participants did also explain that these activities took place in relatively affluent areas.

Others who did not have this within their own local area recognised the need to take the initiative to make the changes, however, often the areas are so deprived or in such poor state that this can be very difficult.

Improved levels of neighbourliness and a sense of belonging to the community are likely to nurture community wellbeing and foster a supportive and nurturing community which can benefit those in lower income groups more than others<sup>63</sup>. All the participants noted the capacity of streets, squares, parks to become shared outdoor spaces that help to foster a strong sense of community.

Architecture Design Scotland guidance on 'caring design<sup>64</sup>' which supports the development of caring places through the incorporation of the following themes: having spaces that are connected, accessible, welcoming, shareable, social, comfortable and accommodating as well as supportive, safe, flexible and beautiful.

When focusing on the regeneration of areas of socio-economic deprivation there is a need to consider the area's present assets and its history and to ask what kind of place is it and what kind of place should it be? Ensuring that people are heard and are able to influence decisions that affect them within their local areas will empower people with a sense of control and strengthen communities<sup>65</sup>.

Using the Place Standard<sup>66</sup> can help structure conversations about place with local communities. The Place Standard is a framework which allows people to consider the physical elements of a place such as its buildings, spaces, and transport links as well as the social aspects, whether people feel they have a say in decision making, or the level of social contact within a place and the sense of identity and belonging that a place provides. The tool has been built jointly by NHS Health Scotland, the Scotlish Government and Architecture & Design Scotland.

<sup>&</sup>lt;sup>63</sup> Uphoff EP, Pickett KE, Cabieses B, Small N, Wright J.A Systematic Review of the Relationships between Social Capital and Socioeconomic Inequalities in Health: A Contribution to Understanding the Psychosocial Pathway of Health Inequalities. International Journal for Equity in Health. 2013; 12(1).

<sup>64</sup> https://www.ads.org.uk/town\_centre\_living\_home/

<sup>&</sup>lt;sup>65</sup> O'Mara-Eves A, Brunton G, McDaid D, et al. (2013). Community Engagement to Reduce Inequalities in Health: A Systematic Review, Meta-Analysis and Economic Analysis. Public Health Res;1(4)

<sup>&</sup>lt;sup>66</sup> NHS Health Scotland. The Place Standard: How good is your place?

To ensure that places are suited to the needs of communities we believe that the Place Standard tool should be consistently used by planners in Local Authorities and the community, by voluntary and private sector organisations to drive up the quality of local places, particularly those suffering the highest disadvantage.

# **Transport**

Connectivity is key, people are living further away from places of work and social activity. All of the research participants agreed that there needs to be an improvement in the transport links within and across cities and these need to be drastically improved in rural areas.

There was also discussion regarding the high costs of public transport and how this resulted in isolating the many people who relied on it as their only means of travel. Participants also recognised the role of the transport system (including how people can access jobs, services and amenities) in enabling social inclusion and helping those on low incomes. There is a need to ensure equity of transport as it is key to the accessibility of employment, shops and services the lack of which can cause significant problems for those on low incomes. Cuts to bus services, rising public transport fares and the closure of local services can all exacerbate the situation.

Participants highlighted the cost of not addressing the transport aspect of social isolation was an increased welfare dependency and isolation from wider society and its benefits. "You can't access your work, or pay for a ticket to go to college then you are stuck on benefits" some people also added that "sometimes you can't pay your bus fare to the job centre and then you are sanctioned or you have to walk". They also highlighted that a lack of suitable transport options can result in the loss of people's independence.

Accessibility by a full range of transport modes should always be a priority; bus and car, foot, bicycle and rail as well as ferry. Accessibility by public transport should be as easy and as attractive as possible for everyone within a city, town or small community. There is a need to calibrate transport provision to meet local needs and circumstances, including frequency, accessibility and costs. Multistage transport journeys should be better integrated with clear and up-to-date timetable information so that people can plan their journeys in advance.

It is also necessary to recognise the contribution of Community Transport and more informal transport arrangements and the role these play in tackling transport inequality and reducing social isolation and loneliness.

Community transport is transport that is provided by members of the community in order to meet the needs of those within their community. It was originally developed to support people who are elderly or disabled. However more recently it has evolved to meet the transport needs of other categories of users who may experience transport disadvantage to the same degree.

Future policy developments should aim to integrate health, housing, environment, community and spatial planning, and transport in order to address loneliness and social isolation and the underlying socio-economic inequalities.

# Section 3: An enabling Government – Supporting people to have control over their lives

Conducting this research has been an exercise in listening to people with experiences of loneliness and social isolation as well those who work with people who experience it. When participants were asked about the role of the Scottish Government in helping to tackle loneliness and social isolation, they had a wealth of ideas. This section provides solutions, influenced by participants, on how might the Scottish Government as a truly enabling administration with a commitment to tackling loneliness and social isolation and its underlying socio-economic inequalities respond to this challenge?

Participants asserted that public policy and decision making needs to be informed by listening to and understanding people's needs on the ground. Policy and decision makers needed to talk to people and those that support them to understand how loneliness and social isolation comes about, what it feels like and what should be done about it.

#### **A Connected Scotland**

The Scottish Government's draft loneliness and social isolation strategy, A Connected Scotland, is a welcome first step towards tackling loneliness and social isolation within Scotland. The draft strategy reflects a Government that is aware of the various policies and strategies that can influence loneliness and social isolation. However, there is no clear sense within the strategy about how the Scottish Government would harness its powers, leverage and commitment to develop policies, legislation and set budgets in order to play its role in resolving loneliness and social isolation and the underpinning socio-economic inequalities.

#### A Whole Government Approach

According to Office of the United Nations High Commissioner for Human Rights the [Scottish] Government has an obligation to ensure the highest attainable standard of health for its citizens and this includes a duty to ensure all citizens have equal access to determinants of [good] health<sup>67</sup>.

The opportunity to harness all aspects of Scottish Government policy including education, employment, transport, welfare, housing and planning, environment and the economy must not be missed. Policies designed to make Scotland stronger, fairer, wealthier and greener should also be designed to make Scotland better connected and mentally and physically healthier but that is not always the case.

A predominant view that the participants held was that "the Government need to start thinking 20 years down the line – what changes do we implement today to improve things for the future?"

<sup>&</sup>lt;sup>67</sup> Office of the United Nations High Commissioner for Human Rights. (2008). The Right to Health Fact Sheet No. 31

It is also necessary to embed prevention and early intervention in order to reduce the number of people who become chronically lonely or socially isolated. There is a need for a range of methods of support to intervene at an early stage.

The solutions to loneliness and social isolation are cross-portfolio and multidisciplinary: it is important to recognise the role of all Scottish Government policies and strategies which can reduce inequalities and improve connectedness in Scotland. All policies and plans should to be assessed for their likely impact on loneliness and social isolation.

# **Human Rights Approach**

VHS would recommend that the Scottish Government employ a human rights approach based on the PANEL principles<sup>68</sup>,<sup>69</sup> and the aims they embody: notably having a human rights based approach at the centre of all policy and decision making, equality and accountability, and providing opportunities for people to participate in decisions and processes that affect their lives.

We would also encourage the Scottish Government to apply an equalities lens to the strategy, remaining mindful of how loneliness and social isolation can be further compounded by social, economic and intersectional inequalities.

# Policy and Legislation for Change

The participants highlighted a range policy related issues that they felt the Scottish Government could tackle. We have taken these issues and grouped them under the relevant policy areas in order to provide a range of policy and legislative recommendation based on what participants said they wanted to change or see happen.

#### **Public Health Reform**

Taking a public health approach to loneliness and social isolation is an idea that VHS has consistently argued for, because of its focus on prevention and health improvement at a population level. Transforming Scotland's health at a population level is the goal of the public health reform programme.

The public health reform agenda will see the establishment of a dedicated national public health agency, Public Health Scotland in 2019, a clearly stated public health role for Community Planning Partnerships as well as a set of national public health priorities which have already been launched. The national priorities cover mental health and wellbeing, place and community, poverty and social inclusion, early years, substance use, diet and physical activity. The public health priorities have a significant focus on population wide, environmental and socio-economic approaches that tackle the root causes of inequalities and if operationalised appropriately could have a significant impact on tackling loneliness and social isolation.

The emerging shared ambition across Scottish Government, COSLA, other public and third sector agencies is for concerted, joined up and strategic action for

<sup>&</sup>lt;sup>68</sup> PANEL stands for Participation, Accountability, Non-Discrimination and Equality, Empowerment and Legality.

<sup>&</sup>lt;sup>69</sup> Scottish Human Rights Commission. A human rights based approach: an introduction

improved population health outcomes in each area. It is not difficult to see how a focus on these national priorities offers scope for improving outcomes in relation to loneliness and social isolation.

#### **Local Governance review**

Recently the Community Empowerment (Scotland) Act 2015 has put an emphasis on people's voices being heard in the planning and delivery of services. However people have been getting involved in local action within their communities in a range of old and new ways; community owned initiatives, community based Housing Associations, community transport initiatives as well as Participatory Budgeting.

Nevertheless, many people still feel that decision making happens far away. Participants had very strong views indeed that "Decision makers sit in their building and make rules and regulations that will affect us without asking us what is it that we want?" There was a general sense that there is very little genuine engagement and that people feel civically disenfranchised. They also highlighted a general lack of accountability from decision makers, "Services, projects and activities that seem to be doing well are just cut and we don't hear why or how they will be replaced" and "No one asks us how we are getting on when services and activities we rely on are taken away".

The Local Governance Review also known as Democracy Matters aims to devolve more power to more local levels by ensuring decision affecting local communities are taken within those communities. The Review is a positive step forward, however, it will be important to take into consideration the voices of seldom heard groups such as people with experience of homelessness, people with long term conditions, learning difficulties, people with mental health problems, the BAME community, people who identify as LGBT+, the gypsy/traveller community, older people, children and young people, people who are carers and cared for, and people involved in the criminal justice system.

It is also important to clearly define local as this can mean very different things in a rural/urban context but also within a single location, for example, Scottish Index of Multiple Deprivation data can show that certain parts of a street can be highly deprived whereas its neighbouring sections are not.

# Social Security and access to benefits

Access to benefits, including in work benefits, and socio-economic disadvantage came through the research as a very important issue and therefore the role of the Social Security (Scotland) Act 2018, if delivered effectively, will be key to tackling the root causes of loneliness and social isolation.

The human rights based approach of the Act which aims to achieve dignity, respect and ensure everyone's right to social security is protected and delivered is a welcome development towards an effective social security system. The Social Security Charter which will 'provide an accessible and understandable articulation of people's rights'<sup>70</sup> and will clarify what should be expected of people accessing the

<sup>&</sup>lt;sup>70</sup> Scottish Government. (2017). Social Security Charter and independent scrutiny

new system and of officials acting on behalf of the new agency, Social Security Scotland, is necessary to ensure that information is consistent.

It is important to avoid any issues arising from the transition from a national to a devolved power to trickle down to service users.

We would encourage the Scottish Government to broaden their engagement on the Charter particularly with underrepresented demographics. Participants spoke about their own experiences of the social security system and barriers they faced including language, inaccessible information, stigma, and general confusion around what they are eligible for and what rights they have.

Our research has raised a number of important issues regarding inaccessibility of the benefits system, the at times incomprehensible or contradictory information provided, the propensity for people to fall through the gaps as well as the mental stress attached to processes such as PIP Assessments, delayed payments as well as sanctions and the resulting rent arrears and financial difficulties.

The Scottish Government and the Scottish Public Health Network are exploring the merit of developing the provision of financial inclusion advice and support within GP practices, this is a positive step that will support a range of people to get the support that they need and better understand their financial circumstances.

There is a need for more consistent delivery and application of information by Department for Work and Pensions staff. Our research has shown that people have very real fears, justified or not, that they will lose their benefits by volunteering. The fear is further compounded by anecdotal evidence regarding DWP staff's inconsistent interpretation of the rules. It is therefore important to ensure that the implementation of information about volunteering whilst on benefits, as well as other benefits related advice is consistent. Our research has revealed volunteering to be very important in relieving people's loneliness and social isolation due to the perceived reciprocity. Volunteering opportunities for all people should therefore be protected and encouraged, especially for the most vulnerable within our societies.

#### Influencing procurement and commissioning practices

The sustainability of funding for community, third and public sector projects and activities that involve or are led by local communities needs to be improved. Participants complained that even when there are activities that help counter and overcome loneliness and social isolation the funding base is so fragile and short term as to be of limited long term value.

A common theme our research participants highlighted was short term funding: "What normally happens is that services get funded for a year and just as we start engaging with the service it gets shut down and is not replaced with anything else".

Participants also noted the importance of organic community development and that "It was better to work within communities and train and develop people's skills and capacity rather than come in develop a single project and leave". "You want to be within a community for a long time to help build people's capacity, something which is really difficult to do with short term project focused funding".

They also said they "would like to see the funding of activity where the service users are facilitated to use and direct new projects, services and activities as they see fit".

"Short term funding creates an ever changing landscape of services, projects and activities. This makes it harder to signpost people to things that may benefit them as they are here today and gone tomorrow".

Workers and healthcare professionals in our research also noted the negative implications of short term funding on the service or activity they are delivering. "If funding is only for a year you may have only just set everything up before the year is over and the funding runs out – no one has used it and you have no money to maintain it".

A predominant view amongst research participants was that: "the expectations of what third sector can deliver are skewed." One participant noted: "I have been working with a range of health services and if you say to them here is £40,000 develop a new public health intervention – they would not be able to do it or would find it very difficult. Yet the third sector are asked to deliver a lot for often very little money – the expectations on third sector capacity to fill in for statutory services is unrealistic".

## **Health and Social Care Integration**

It is important to clarify how Health and Social Care Partnerships are expected to approach mental health, loneliness and social isolation, to avoid these being understood purely in terms of clinical interventions and to ensure the resourcing of wider non-clinical interventions and a real move towards community based support.

The work of Integrated Joint Boards (IJB's) should provide opportunities for the public sector to support their local communities by planning investment, development and services according to their needs<sup>71</sup>. However, VHS has heard from a wide range of third sector organisations that the engagement of Integration Authorities with the third sector, service users and carers is uneven across Scotland, and that partnerships often fail to include non-voting partners in a consistent and meaningful manner<sup>72</sup>. The voices that could reflect issues of loneliness and social isolation are not reflected in the arenas where change can occur. Several IJBs have developed support mechanisms to enable carer representatives to feel fully supported and enabled to participate, however, this is an exception.

A leading cause of loneliness and social isolation in older age is declining mobility and a fear of falling<sup>7374</sup>. The Scottish Government pledged to develop a strategy, due for publication in April 2019 and an Older People's Framework<sup>75</sup>. As this is a tangible

<sup>&</sup>lt;sup>71</sup> NHS Health Scotland (2016). Place and Communities

<sup>&</sup>lt;sup>72</sup> Voluntary Health Scotland. (2017). VHS Response to Health and Sport Committee Call for Evidence looking into the engagement between Integration Authorities and third sector, patients and carers.

<sup>&</sup>lt;sup>73</sup> Hajek, A., König, HH. (2017). The association of falls with loneliness and social exclusion: evidence from the DEAS German Ageing Survey

<sup>&</sup>lt;sup>74</sup> World Health Organisation. (2007). Global Report on Falls Prevention in Older Age

<sup>&</sup>lt;sup>75</sup> Scottish Government. (2018). Delivering for today, investing for tomorrow: the Government's programme for Scotland 2018-2019

solution to reducing loneliness and social isolation for this group of society and given the associated costs of unintentional harm and unplanned hospital admission both the strategy and framework could usefully reflect the social and environmental factors which need to change to enable preventative interventions to be prioritised.

## **Mental Health Strategy**

Due to the two way relationship between poor mental health and loneliness and social isolation it is imperative that the aims and objectives of the current Mental Health Strategy are assessed for their impact on loneliness and social isolation.

There is a critical need for close alignment between the Mental Health Strategy and the finalised loneliness and social isolation strategy, *A Connected Scotland*.

The Scottish Government should look at the recommendations in NHS Health Scotland's 2015 report, *Good Mental Health for All*<sup>76</sup>. These included a call for an alignment of activity towards a shared vision – an integrated strategy for mental health balancing promotion, prevention, treatment and care.

## **Primary Care Reform**

Primary care reform has the potential to support people who are lonely and isolated by providing health care that is compassionate and holistic, resolving a person's medical as well as the underlying social issues.

Multidisciplinary Teams within GP practices which include Community Link Workers could also, if delivered effectively, provide an opportunity to support people who are suffering from loneliness and social isolation. These teams could also prevent people from becoming chronically lonely and social isolated by linking them to support early on. The Scottish Government has provided investment to enable the development of 250 Community Link Workers to work in GP surgeries to support patients connect with non-medical sources of support or resources in the community which are likely to help with their health problems. VHS was commissioned by the Scottish Government to undertake research and produced a report, *Gold Star Exemplars*<sup>77</sup>, setting out the extensive and varied nature of third sector approaches to community link working across Scotland.

There needs to be better information about what services - statutory, private, community or third sector based - there are within communities and how to access them – this will improve signposting as well as access to existing community resources.

## **Inclusive and Sustainable Growth**

Participants emphasised poverty, in-work poverty and socio-economic disadvantage as underpinning inequalities that resulted in loneliness and social isolation. The

<sup>&</sup>lt;sup>76</sup> NHS HS. (2016). Good Mental Health for All

 $<sup>^{77}</sup>$  Voluntary Health Scotland. (2017). Gold Star Exemplars: Third sector approaches to Community Link Working across Scotland

Scottish Government's Inclusive Growth agenda can be a potential enabler or disenabler in tackling loneliness and social isolation.

Economic growth is slowing down and it will only be sustainable if it is based on equity and inclusivity. Poverty is bad for the economy and results in inequalities within society that mean fewer people have access to money and resources, there are lower levels of social mobility and people cannot take advantage of human capital and connections<sup>78</sup>. An inclusive growth agenda should seek to enable people to fulfil their own potential, and in doing so the potential of the economy they are a part of.

Connecting people up to the opportunities that exist in the labour market through better education, transport and employment support is vital. Creating places that include accessible local industries, services and facilities, thus helping to secure employment, enterprise and training opportunities for residents and attracting key workers<sup>79</sup>.

Neighbourhood businesses should be supported in order to protect and promote friendly, supportive local economies. Local businesses are key for thriving communities because of the opportunities they create for local people, the reinvestment of money and resources back into the local economy due to a local supply chain but also because they often act as informal conduits of social contact and promote a sense of community spirit and connectedness.

The social and economic inequalities as well as the environmental barriers such as planning of places and spaces, well-resourced and supported communities and the delivery of compassionate services that underpin loneliness and social isolation should also be improved and rectified.

## Planning and development

The Planning (Scotland) Bill offers the opportunity to improve health and wellbeing by ensuring appropriate housing supply to meet the needs of local populations, safeguarding access to greenspace and services, providing opportunities for physical activity and social connection, and developing spaces that are safe.

It is of concern that the Planning Bill may remove targets for social housing. Without social housing targets it may be difficult to remedy the shortage of affordable housing.

Community facilities should be safeguarded within the Local Development Plans because of their protective effect on the health and wellbeing of communities and their role as a space for increased connectedness and community cohesion.

There is a need for better co-ordination of economic development, housing, transport and retail and investment in infrastructure that improves connectedness.

<sup>&</sup>lt;sup>78</sup> Joseph Rowntree Foundation. (2017). What is inclusive growth and why does it matter?

<sup>&</sup>lt;sup>79</sup> Town and Countryside Planning Association (2017), Creating health-promoting environments.

## **Transport**

The development of the Transport Bill has the potential to offer flexible and low cost travel options. Participants identified a lack of mobility due to high costs and often non-existent or few appropriate travel options and the implications of this on loneliness and social isolation. The Bill should explore the possibility of empowering Local Authorities to make localised transport decisions and offer their own solutions if commercial transport options are lacking.

Community transport is also a key resource in supporting mobility where public transport is not available. This resource must be protected and supported so that it can continue to deliver mobility as a service to many often marginalised communities.

The Bill should also explore the possibility of smart ticketing that can also be used to pay for alternative modes of transport such as community transport, taxis and informal arrangements in rural settings and areas that are underserved by regular, cost-effective and efficient public transport.

There should also be provision for up-to-date, clear and accessible transport information and more should be done to integrate the links between multistage public transport journeys.

Spatial and transport planning should be brought together in order to create places that are well connected and offer choice in terms of transport options. This process can help to develop walkable neighbourhoods by creating high connectivity (for example, easy routes between destinations), good pedestrian and cycling facilities (such as good street design, lighting, well-maintained pavements, cycle routes, traffic calming measures), and good accessibility (easily reached destinations and facilities, greenspace and strong transport links)<sup>80</sup>.

It is essential that places are planned, located and designed strategically to ensure good connectivity between residential areas and employment, retail, services and amenities, predominantly by public transport and active travel modes.

People's transport choices are influenced by the distance that they have to travel to conduct their daily routines as well as the way in which they perceive their physical environment. Improving the quality of the built environment and improving the connections between places can encourage people to make more sustainable travel choices that impact positively on their health such as walking and cycling. Well-connected and attractive public places and streets can encourage people to exercise and make active travel choices.

## The Role of Education

It is important that education and support is developed from early years' right through to higher education that enables our children and young people to develop resilience and positive coping mechanisms. Education itself should play a role in teaching

<sup>&</sup>lt;sup>80</sup> Glasgow Centre for Population Health (2013). The built environment and health: an evidence review.

children and young people *how* to learn and understand the world around them not *what* to learn and understand.

Our research participants highlighted some examples of resilience building programmes and activities that can support children and young people; these include: "Pre-school programmes on school readiness, helping young people develop communication, social and emotional skills, anti-bullying programmes in schools, support to stay safe online, Personal, Social and Health Education (PSHE) at all levels of schooling, including Life Skills for older children, mental health support on site in all educational settings, peer counselling, local befriending or mentoring services, and opportunities to help others through volunteering or working in the community".

A study into life course effects of loneliness and social isolation shows that 'Initiatives which focus on general self-efficacy and competence self-esteem, and on building social skills and positive relationships would seem to have some potential for...protection against chronic loneliness<sup>81</sup>'.

The charity Children's Health Scotland has argued that it is important to support children with long term or life-limiting conditions to avoid them becoming socially isolated, excluded and lonely. Their proposals include support to assist children back into school after periods of absence (e.g. due to hospitalisation), equality training for staff and pupils, flexible school hours, and classes that promote social interaction, such as drama and art.

Afterschool groups and clubs that are person centred can help them feel connected. It should be viewed as a human right that children and young people with long term conditions have access to and are included in activities that other children and young people enjoy. Services need to listen to and work with them to develop services, reduce stigma and break down barriers<sup>82</sup>.

Participants wanted to ensure that public services such as the DWP, NHS, GPs are compassionate and understanding to people's needs and lived experiences. They also highlighted the importance and need for one-to-one level informal connections.

## Compassion

The Royal College of Physicians of Edinburgh in their conference *A Patient's Tale*, defined compassion as: 'recognising pain, distress or suffering and taking action to address or relieve it'83. The conference emphasised that compassion involves taking positive action to prevent, ameliorate or remove a person's problem or distress. We believe that health, social care and other public services need to do more to promote compassion, in order to improve service users' experiences of services.

<sup>&</sup>lt;sup>81</sup> Jopling, K., S. Serwanja, I. (2016). Loneliness Across the Lifecourse: A Rapid Review of the Evidence. Calouste Gulbenkian Foundation.

<sup>&</sup>lt;sup>82</sup> McCann, A., Mackie, P., Conacher, A. (2017). Social Isolation & Loneliness: What is the Scope for Public Health Action? Scottish Public Health Network

<sup>83</sup> Royal College of Physicians of Edinburgh. (2017). A patient's tale: how compassionate is our NHS?

Understanding the nature and importance of compassion not only in our roles within health and care but in all services provided to the public, regardless of the sector delivering them, is key to ensuring people feel they are understood, respected and that they matter. Participants felt strongly about the need to have compassionate services that see the person not a label, recognise people's lived experience and circumstances and to try to do something to alleviate people's distress.

As one participant highlighted "It is not just Mr X, suffering from Colon Cancer in room 19 but a person with their whole history. We need to do more to understand how people are coping and support them with their physical and psychological distress".

A recent report from the Public Accounts Committee has criticised the DWP's 'dismissive attitude' towards the lived experiences of claimants, citing that their indifference is 'failing claimants'84.

Participants argued that there was a need for cultural change and that treating people with dignity and respect should be at the centre of all interactions, especially those that occur in situations of power imbalance. Situations of power imbalances that the participants highlighted include those that occur between employers and employees, service providers and service users; between a health professional and a patient, for example.

## The Third Sector as an Enabler

The role of the third sector in supporting people who are lonely or isolated is well intertwined within this report. Participants have been involved with the third sector either as a user of services, a volunteer or a worker and recognised the value of the third sector in tackling loneliness and social isolation and empowering people with skills and confidence in order to have more control over their lives.

It is widely recognised that third sector organisations are often able to engage and develop the trust of vulnerable people in a way that statutory services sometimes find hard to do. VHS's report, Living in the Gap: A voluntary sector perspective on health inequalities in Scotland<sup>85</sup>, drew attention to the view that engaging vulnerable groups is what the voluntary sector does best.

The contribution of voluntary health organisations and other types of third sector organisations such as social enterprises, faith and community groups should not be ignored. To do so would be to overlook an extensive pool of resource, experience and expertise. Many are organisations embedded at the heart of communities throughout Scotland and already working effectively with public sector colleagues, through community planning or health and social care integration partnerships.

 <sup>&</sup>lt;sup>84</sup> Commons Select Committee. (2018). Public Accounts: Universal Credit https://publications.parliament.uk/pa/cm201719/cmselect/cmpubacc/1183/118305.htm#\_idTextAnchor002
 <sup>85</sup> Voluntary Health Scotland. (2015). Living in the Gap: A voluntary sector perspective on health inequalities in Scotland.

#### Kindness

Kindness and compassion is a core value in the Scottish Government's relaunched National Performance Framework<sup>86</sup>. The Carnegie UK Trust alongside the Joseph Rowntree Foundation have worked with seven organisations to test what can be done to encourage kinder communities. They have explored ideas around the importance of places and opportunities to connect, and the intrinsic values underpinning interactions and relationships with a central focus on how kindness and everyday relationships can affect change and support the wellbeing of individuals and communities.

Their research has also identified 'factors that get in the way of engaging and encouraging kindness both in individuals and organisations, including real and imagined rules relating to risk; funders and policy makers valuing the formal and organisational over the informal and individual; and modern definitions of professionalism and good leadership crowding out everyday kindness and intuitive human interactions'<sup>87</sup>.

Participants in our research were also asked about kindness and its role in loneliness and social isolation. Participants described how they felt towards acts of kindness, "[People] feel that they are a burden on others and don't want to intrude. We often ask people to come over for Christmas and we know deep down inside they really want to come but they don't because many times they don't want to accept that they are lonely and other times because they don't want to feel a burden and put other person out – they would rather be alone than burden anyone". Participants explained that because people were not able to reciprocate they did not want to engage, "people don't want to accept charity" or feel that they are passive recipients of services.

Participants felt strongly about the need for people's basic rights to be met; a right to a warm home, nutritious food, and access to fair opportunities and adequate resources. If they had access to these then they would not feel ashamed of accepting kind offers from people as they would be able to reciprocate and have relationships based on equality and mutual respect.

Since the former Prime Minister Margaret Thatcher's comment "...there's no such thing as society. There are individual men and women and there are families. And no government can do anything except through people, and people must look after themselves first," actions such as austerity and Welfare Reform have further dissolved the concept of society and caused a shift away from investing in people with the least power.

There is a need now more than ever with over 9 million people in the UK, almost a fifth of the population<sup>88</sup>, saying they are always or often lonely and around 8.9 million people living in absolute low income even before their household costs are

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<sup>&</sup>lt;sup>86</sup> Scottish Government. (2018) National Performance Framework

<sup>&</sup>lt;sup>87</sup> Ferguson, Z. (2016-2019) - https://www.carnegieuktrust.org.uk/project/kinder-communities/

<sup>&</sup>lt;sup>88</sup> British Red Cross and Co-Op. (2016). Trapped in a Bubble.

covered<sup>89</sup>, to resolve the socio-economic inequalities within society that underpin loneliness and social isolation.

## **Next Steps for VHS**

VHS will present the report and the analysis to the research participants who have been keen to see how their perspectives are represented and ask them how to proceed with its dissemination.

VHS are interested to know if participants agree with how we have presented their views, if the analysis resonates with them and to ask how this compilation of their views into something tangible has affected their perspectives and thinking on the issue of loneliness and social isolation.

Areas for future research include exploring the loneliness and social isolation experienced by people whose mobility, social connections and access to services and amenities are significantly constrained such as prisoners, ex-offenders, people with disabilities and people in long-term care or hospitals. It would also be valuable to explore the loneliness and social isolation experiences of LGBT people who are often most underrepresented especially in literature around loneliness and social isolation and can face multiple triggers throughout their life stages.

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<sup>&</sup>lt;sup>89</sup> House of Commons. (2018). Poverty in the UK: Statistics

## Appendix 1: Discussion Guide - Service Providers and Service Users

## Introductions (5 mins)

#### Introduce self and VHS

Introduce the research: Also introduce the Scottish Government and role of consultations

- Explain that the group will last up to 90 minutes
- Provide reassurances of anonymity and confidentiality. Explain that no information about individuals will be passed on to anyone outside the research team.
- No right or wrong answers. Give everyone a chance to speak.
- Request permission to record interview.
- Housekeeping (fire alarm, toilets, mobile phones etc.)

Do you have any questions you'd like to ask before we start?

About respondents:

Perhaps before we begin you could each tell us a little about yourself

Start recording after introductions.

## **Understanding Service Providers (20 mins)**

- What do you understand by loneliness?
- What groups of people can experience loneliness?
- Why do you think people experience loneliness?
- Do you think that loneliness is a fact of life or do you think that it is something that needs to be addressed?
- Who do you think is responsible for addressing loneliness?
- What makes you say that?

## Experience (15 mins)

- What type of services or activities do you provide that may overcome these issues?
- Why do you think these services and activities work?
- How do you ensure you get access to hard to reach demographics?
  - What are the types of things that make it difficult? What do you think stops people from accessing services in their communities – what are the barriers?
- What are the barriers to delivering your service?
- What type of services would you like to deliver that you are currently not able to?

## **Understanding Service Users (20 mins)**

- What do you understand by loneliness?
- What groups of people can experience loneliness?
- Why do you think people experience loneliness?

Do you think that loneliness is a fact of life or do you think that it is something that needs to be addressed?

## **Experience (15 mins)**

- Can you think of a time when you personally experienced loneliness?
- How did that feel?
- What were the triggers?
- how did you or can you overcome it?
  - O What are the types of things that make it difficult?
- Who do you think is responsible for addressing loneliness?
- What makes you say that?

## What works (30 mins)

As you know, the Scottish Government is currently consulting on a draft strategy, which aims to tackle loneliness and social isolation in Scotland.

The Scottish Government have identified a number of underlying issues that can be improved to tackle loneliness:

• How can the Scottish Government improve physical spaces to help tackle loneliness? [Prompt cards: create more parks and recreational spaces, more spaces within existing structures such as libraries, communal areas in buildings]

- What do you think the Scottish Government should be doing to tackle low income and inequality?
- How can transport be improved to reduce loneliness?
- How can health services better support people who are lonely?
- How can the Scottish Government support local communities to help build stronger social connections?
- I am interested to know what barriers to service delivery the Scottish Government could remove that would help your organisation?

[Allow time for discussion before moving on to next exercise]

- What role do services in the local community offer to support people who suffer from loneliness?
- What types of services or activities do you think work?
- What do you think stops people from accessing services in their communities what are the barriers?
- What do you think community organisations can be doing more of to reduce loneliness and how can they:
  - Ensure equality of opportunity between different groups
  - Encourage good relations within and between different groups

## [If there is time]

What role can local business play in reducing loneliness?

## Kindness (10 mins)

- What role does kindness play in reducing loneliness?
- What role does kindness play in your organisation and the services/activities you deliver?
- Are there any barriers or risks to being kind?
- How can we promote kindness and kinder communities?

## Wrap up (5 mins)

#### Closing

Is there anything else, apart from the things we have already discussed today, that you would like us to convey to the Scottish Government about what it should be doing to reduce loneliness and to promote communities that are more connected? Anything else?

## **Appendix 2: Consent Form**

### **Focus Group Consent Form**

Research project title: Experiences of Loneliness and Social Isolation (working title)

Research investigator: Kiren Zubairi

- I agree to participate in the focus group carried out by Kiren Zubairi of Voluntary Health Scotland, to aid with the research into experiences of Loneliness and Social Isolation.
- I have read the information sheet related to the Experiences of Loneliness and Social Isolation research project and understand the aims of the project.
- I am aware of the topics to be discussed in the focus group.
- I am fully aware that I will remain anonymous throughout data reported and that I have the right to leave the focus group at any point.
- I am fully aware that data collected will be stored securely, safely and in accordance with Data Collection Act (1998).
- I am fully aware that I am not obliged to answer any question, but that I do so at my own free will.
- I agree to have the focus group recorded using a Dictaphone, so that key messages may be extracted after the focus group is held. I am aware that I have the right to edit the key messages attributed to the Focus Group I am involved in, once it has been completed.
- I am aware that I can make any reasonable changes to this consent form.
- I am aware and consent to the key messages extracted from the Focus Group to be re-used in other reports and publications.

Printed Name	Date	
Participant's Signature	Date	

## **Contact Information**

If you have any further questions or concerns about this study, please contact:

Name of researcher: Kiren Zubairi

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Tel: 0131 474 6187

E-mail: Kiren.Zubairi@vhscotland.org.uk

You can also contact Kiren's Manager Claire Stevens: Claire.Stevens@vhscotland.org.uk

The Zubairi Report presents and analyses findings from a qualitative study into the loneliness and social isolation experienced by under-represented demographics in Scotland. It gives voice to a range of people who have been less visible and less heard in the debate on loneliness and social isolation. It uses their experience and views as a basis to explore what could be done at a government, societal and individual level to address the issues identified.

# get involved

## we welcome new members

www.vhscotland.org.uk/get-involved

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