

Cross-Party Group on Health Inequalities

6 pm-7.30 pm, Wednesday 4th October 2023

Draft Minute

Present

MSPs

- Brian Whittle MSP
- Emma Harper MSP

Invited guests

- Laura Robertson, Senior Research Officer, The Poverty Alliance: Scottish Minimum Income Guarantee
- Dr Naomi Richard, Senior Lecturer in Social Science at University of Glasgow: Dying in the Margins in conjunction with Marie Curie

Non-MSP Group Members

Pervin Ahmad, Saheliya
Lauren Blair, Voluntary Health Scotland
Terence Canning, UK Sepsis Trust
Christine Carlin, Voluntary Health Scotland
Kate Cunningham, Energy Action Scotland
Alan Eagleson, Terrence Higgins Trust
Sarah Edwards, The Breastfeeding Network
Helen Forrest, Children's Health Scotland
Paula Fraser, Voices of Experience Scotland
Rob Gowans, The Health and Social Care Alliance Scotland (the ALLIANCE)
Grace Gracie, Families Outside
Toni Groundwater, Families Outside
Jen Hardy, Cancer Card
Roisin Hurst, Voluntary Health Scotland
Una MacFadyen, Children's Health Scotland
Angus Maclean, Befriending Networks
Janis McCulloch, Myeloma UK
Agnieszka Morrison, Feniks
Rob Murray, Red Cross
Justina Murray, Scottish Families Affected by Alcohol and Drugs
Nell Page, Salvesen Mindroom Centre
Mark, Quilietti-Bird, NHS Lothian
Tilly Robinson-Miles, Food Train
Lesley Ross, Glasgow Council on Alcohol

Kimberley Somerside, Voluntary Health Scotland
Claire Stevens, Voluntary Health Scotland
Sheila Thomson, Community Renewal Trust
Sarah Van Putten, LifeCare
Ellie Wagstaff, Marie Curie
Tom Wightman, Pasda

Non Group Members

Sarah Boath, SCDC
Margaret Brown, NHS Highland
Gary Meek, Blue Triangle Chand Kaur, PCOS Relief
Kirsty McNab, Scottish Sports Futures
Stephanie Morrison, Robert Gordon University
Karen Swift, Turning point Scotland

Apologies

Paul O’Kane MSP, Donald Cameron MSP

Agenda item 1 Annual General Meeting

Claire Stevens welcomed everyone and apologised on behalf of Emma Harper MSP who was running late. Brian Whittle MSP convened the start of the meeting beginning with the invited speakers to allow Emma Harper to join us.

Agenda item 2 Election of Convenors

Claire Stevens, VHS, proposed Emma Harper and Brian Whittle were re-elected for a further term of office as co-Convenors. Paul O’Kane MSP stepped down as co-convenor, Claire thanked him for his time.

Agenda item 3 Appointment of Secretary

Brian Whittle proposed Voluntary Health Scotland were re-appointed Secretary for the next 12 months, Shiela Thomson Community Renewal Trust seconded.

Agenda item 4 Annual Return

VHS will prepare the Annual Return as required by the Scottish Parliament and will submit this once signed by a Co-Convenor. This will be publicly available via the CPG web page.

Agenda Item 5 Any other business

There was no other competent AGM business.

Agenda Item 6 Business Meeting: “A decent and dignified life”- Challenge Poverty Week

The Minutes from the meeting held on the 14th June 2023 were approved. These were proposed by Tilly Robinson-Miles, Food Trian, and seconded by Rob Gowans, the Health and Social Care ALLIANCE.

Agenda Item 7 New Members

The following new members were approved:

- [MECOPP](#)
- [Myeloma U.K.](#)

Janis McCulloch, Myeloma UK, explained myeloma was a blood cancer which was treatable, she also noted the specific health inequalities for this specific condition. She explained Black people are more likely to have Myeloma and face delays in diagnosis.

MECOPP: By working in partnership with carers, voluntary organisation and statutory bodies, MECOPP actively seeks to challenge and dismantle barriers that deny Black and Minority Ethnic carers access to health, social work and other social care services in Edinburgh, the Lothians and further afield.

Agenda Item 8 Discussion Topic: “A decent and dignified life”- Challenge Poverty Week

Presentations by:

- Laura Roberts, Senior Research Officer, The Poverty Alliance: Scottish Minimum Income Guarantee

Laura explained the Poverty Alliance was a national anti-poverty organisation, which ran Challenge Poverty Week (CPW) in Scotland. She explained the ask for the day of CPW was adequate incomes. She started by explaining people’s right to social security and that the Minimum Income Standard was what was needed to have a decent standard of living, including being able to participate in society. By this standard a single person needed to earn £29,500 a year to reach a minimum acceptable standard of living, but this had likely increased during the rising cost of living.

She explained the Minimum Income Standard was not broken down based on protected characteristics, its only by household size. She outlined the gaps in social security provision for different household types. Laura explained disabled people were more likely to face hardship and live in poverty and in very deep poverty. She outlined the households who were most likely to be struggling in terms of income. On average disabled households needed an additional £975 a month to have the same standard

of living as non-disabled households. She said the Scottish Government had committed to reviewing the amount of adult disability payments.

Laura went on to explain the Minimum Income Guarantee, which was a key policy ask from the Poverty Alliance. The Scottish Government had committed to looking at what steps would be needed to implement it. A Minimum Income Guarantee would be set to ensure an acceptable standard of living that promotes dignity and a decent quality of life. It would take into consideration protected characteristics and variations in what different people need. Laura emphasised it was different to a Universal Basic Income.

Laura outlined the different steps that would be needed to achieve a Minimum Income Guarantee, including things like better wages, social security reform and targeted payment to keep everyone above the set minimum income level. Collective public services were another important aspect of this, for example childcare.

A steering group was created in 2021 and an expert by experience panel to take this explorative work forward.

- Dr Naomi Richard, Senior Lecturer in Social Science at University of Glasgow: Dying in the Margins in conjunction with Marie Curie

Naomi provided a moving presentation on her recent research in conjunction with Marie Curie on dying in the margins. She explained the research was designed to uncover the reasons for unequal experiences in death and provided lived experience testimonies throughout her presentation. It followed the stories of participants who were all dying at the time of the study, each was given a camera to photograph their own perspective and additional photographs were taken by the researchers to document their experience.

The first theme Naomi explored was the costs of dying at home, be it electricity, taxis, heating, charging equipment or paying for care when state funded care was deemed insufficient. She noted it was highly unlikely someone could die at home if they didn't have a friend or family carer who could support them.

In terms of living conditions, she highlighted how noise pollution, poor housing and cramped conditions could significantly impact people's experience. She shared the testimony of Liz who was blamed by her landlord for the huge mould issues she was experiencing in her flat while she was dying at home. Naomi also explained people living in multistorey flats struggled to move around which presented an issue for access for health and social care professionals. Stair lift installations are at the discretion of local authorities, and people dying were less likely to receive these as it wasn't seen as a long-term investment. She said some participants in the study stayed indoors while they were dying because their outside environment was not hospitable, this added to their social isolation.

Hospices and special places in the community were often seen as safe places for participants. This underlined the importance of access to physical spaces in communities and safe hospice space.

Naomi explained 'home and identity' was another key finding of importance. Staying at home allowed people to maintain their identity, even with the extra cost. She shared

the story of Marie who spent the little money she had while she was dying creating a sanctuary in her flat with things like face masks and small pampering treats. Having clothes and belongings which were their own was also important. The presence of pets at home was a key support for people's identity.

Being at home also enabled some participants to maintain a sense of autonomy especially for those who felt restricted by being in an institution. Naomi outlined that poverty and experiences of trauma had an extreme correlation which can mean people have negative connotations of institutions – this was something care providers could better consider and cater for. Naomi made an important point that informal carers enable people's autonomy but they themselves can also be living on the margins and facing their own challenges.

Naomi ended by stressing the importance of these testimonies in the context of rising poverty levels and rising numbers of people dying in the UK. She said the number of people dying in the context of deprivation was increasing. While services cannot always prevent inequality, they can mitigate against it and remove barriers to things like social security when people are dying.

Questions:

- **UBI/MIG:** Brian Whittle MSP said universal income was something which was being discussed a lot in parliament, and his party came to the conclusion it was cost prohibitive. Laura explained that a Minimum Income Guarantee was very different to Universal Basic Income, noting it was a newer concept which is only really being discussed in Scotland. She said the steering group was currently costing it as a proposal. The Minimum Income Standard that the Joseph Rowntree Foundation had worked on was well known and provided a floor for what people needed to live. But the value of Minimum Income Guarantee could be different, it was more about things like employers, using social security and creating more affordable childcare. Brian Whittle asked how this could be quantified in the Scottish context for example between someone living in Edinburgh or someone in a more rural area. Laura said the Robertson Trust was leading this work and could provide more information. Emma Harper also said the Health, Social Care and Sport Committee had discussed Minimum Income Guarantee a few times.
- **Autism and Social Security:** Tom Wightman spoke as the father of someone with autism, he explained his son had moved into supported accommodation a year ago, but his benefits had not yet changed to accommodate this. For example, he had not yet been given money for a mobility care. Tom explained this was leading to significant misspend and wasting the social carers time. Laura suggested Tom reach out to her so she can sign post him to some organisations who may be able to provide advice. Emma suggested Tom contact his MSP too and asked him to message her directly.
- **Older People:** Sarah Van-Putten, LifeCare, asked whether Naomi's study looked at older people's experience while dying. Naomi explained the study didn't have a lot of older people, partly due to the way they recruited. She suspected though that for older people living at home there would be very similar issues. Especially with regards to carers and having someone there for support. She said there was a growing concern about the number of older people dying alone. There were also issues around carers being older. Naomi noted though that older people were less likely to die in poverty due to the state pension which was more than most working

age benefits. She highlighted a Marie Curie campaign for accelerated access to state pension when someone had a terminal illness.

- **Ethnic Minorities:** Pervin Ahmad, Saheliya, noted that for ethnic minorities there was a move away from younger people looking after older people in the family. It was becoming less likely that older people would be supported by the community and increasingly they were living in poverty. She also noted the increased price of a halal diet which can be three times the price in terms of chicken, which increases people's living costs too.

Agenda item 9 Any other competent business

There was no other competent business.

Agenda item 10 Date and topic of next meetings

Emma Harper MSP said she would be following up with Russell Gunson on the Minimum Income Guarantee. She also suggested a future joint meeting with the CPG on Wellbeing Economy as many of the themes discussed today were cross-cutting.

Claire Stevens explained VHS was still trying to pursue some of the issues discussed at the last meeting on racialised health inequalities and she was due to meet with the Scottish Government's racialised health inequalities team shortly. Claire suggested we revisit this as a topic in future and Emma agreed with this. Brain said he had done some work with the Chief Superintendents Scotland on racism training with two high profile Olympians. He underlined the importance of having someone in the conversations who's "not afraid to say it how it is" and suggested they would be a great asset to any future conversations on this. Emma suggested we bring back the training being carried out by various organisations at a future meeting to share learning.

Emma suggested people email Lauren or Claire with suggestions for future meetings.