CVDR/S6/22/17/1

COVID-19 Recovery Committee

17th Meeting, 2022 (Session 6), Thursday 23 June 2022

COVID-19: communication of public health information:

Introduction

1. At its meeting on 28 April 2022, the Committee agreed to hold an inquiry into the effective communication of public health information and tackling misinformation. The purpose of this inquiry is to hear from experts and stakeholders about the effective communication of public health information, evidence-based decision-making and tackling misinformation drawing on the experience of the COVID-19 pandemic.

2. The inquiry has the following aims—

- To understand the challenges, including the existence of any misinformation and disinformation, faced by government in communicating public health messages in the pandemic to date and to consider what could be done by government to tackle these issues going forward;

- To consider whether public health information about COVID-19 is accessible to and meets the needs of specific audiences going forward, including people in the shielding category and communities where there has been below average uptake in vaccination to date;

- To understand how scientific information about personal health risks and risks to wider society can be best used to inform decision-making and public health messaging.

3. At this meeting, the Committee will take evidence on the second two aims of the inquiry from the following panel of witnesses—

- Adam Stachura, Head of Policy and Communications, Age Scotland;

- Danny Boyle, Senior Parliamentary and Policy Officer and National Coordinator of the EMNRN, BEMIS and Ethnic Minority National Resilience Network;

- Gillian McElroy, Policy and Information Officer and Jonathan Reid, Scottish Sensory Hub Co-ordinator, Health and Social Care Alliance Scotland (the ALLIANCE);

- Dr Sally Witcher OBE, Independent consultant on disability equality;

- Professor Jill Pell, Director of the Institute of Health and Wellbeing, University of Glasgow.

4. Further background information on the witnesses and issues for discussion can be found in SPICe paper 2 for this meeting.

Evidence

5. The Committee received written evidence from the following organisation in advance of this meeting which is attached at the Annexe to this note—

- BEMIS
- Health and Social Care Alliance Scotland
- Dr Sally Witcher OBE

6. In advance of the formal evidence sessions, on 19 May 2022, the Committee held an informal discussion with fellows from the Royal Society of Edinburgh to discuss the findings of its Post Covid Futures Commission. This session pertained to the third aim of the inquiry above regarding the use of scientific information in decision-making and public health messaging. A note of that discussion has been published on the Committee's website.

7. The Committee then took evidence on 26 May on the first two aims of the inquiry, the papers and transcript from the meeting can be found on the Committee's website.

Next steps

8. The Committee will take evidence on its inquiry from the Minister for Public Health, Women's Health and Sport at its meeting on 30 June 2022.

Committee Clerks
June 2022

ANNEXE

Written evidence submitted by BEMIS

Vaccine Information Fund

Report to Covid Recovery Committee

June 2022

BEMIS
Empowering Scotland's Ethnic and Cultural Minority Communities

ETHNIC MINORITY
NATIONAL RESILIENCE NETWORK

Vaccine Information Fund

Timeline:

- 8th December 2020 – First Vaccine Administered in UK
- 9th December 2020 – EMNRN meet with SG Vaccine Officials **(Note contained See Annex A)**
- 14th December 2020 – Kent variant reported by BBC
- 5th January 2021 – Scotland enters full lockdown
- 4rth February 2021 – 27th February 2021 BEMIS Scotland survey analysis on vaccine hesitation in minority ethnic groups
- 25th February 2021 BEMIS Launch Vaccine Information Fund
- 16th March 2021 – BEMIS submit briefing to SG Inclusive Vaccinations Group **(Briefing contained See Annex B)**
- March 2021 – October 2021 VIF Deployed
- 10th August 2021 – African, Caribbean and Black Inclusive Vaccinations Group Meets (https://bemis.org.uk/emnrn/subgroups/)
- December 2021 – OMICRON (VIF expands to include mental health support and tackling destitution)
- January 2022 – Research commissioned into African, Caribbean and Black Vaccine Hesitancy
- March 2022 – Fund ends
- August 2022 – Launch of African, Caribbean and Black Research with Cabinet Secretary for Health Humza Yousaf MSP

Vaccine Information fund outcomes and learning

- ✓ Scottish Government civil servants in the Race Equality Unit moved swiftly to respond to the concerns and findings of the February 2021 survey on vaccine hesitation

- ✓ Minority ethnic communities mobilised at an unprecedented rate to engage their membership and broader communities in the vaccine information fund to increase informed consent

- ✓ 51 self-identified minority ethnic communities participated in and benefitted from the VIF. The level of diversity is an indication of the increasing demographic changes in Scotland and need for health care to evolve to respond to a changing population.

- ✓ Between March – September 2021 during first vaccination campaign to receive 1rst and 2nd doses uptake increased across all minority ethnic groups

Table 20: % uptake of first dose of COVID-19 vaccination on the 1st of May 2021 and the 24th August 2021, by age group and ethnic group

Age Group	White		Mixed/ Multiple		Asian		African		Caribbean or Black		Other	
	01-May	24-Aug	01-May	24-Aug	01-May	24-Aug	01-May	24-Aug	01-May	24-Aug	01-May	24-Aug
80+	95.9	96.0	88.0	88.5	84.6	85.4	75.0	76.3	93.0	93.0	86.2	87.0
75-79	97.4	97.6	92.6	92.6	87.1	88.2	71.4	76.2	81.5	81.5	85.5	87.6
70-74	96.8	97.2	85.6	86.4	88.2	90.1	72.3	75.3	92.9	92.9	83.4	86.1
65-69	96.0	96.6	85.6	88.5	88.3	91.3	77.5	83.3	83.2	85.8	80.0	82.7
60-64	94.9	95.8	81.7	84.4	87.5	90.7	71.9	77.0	81.2	85.6	78.2	81.8
55-59	93.5	94.9	82.9	86.8	84.5	89.6	73.7	80.0	77.1	81.6	75.6	80.5
50-54	89.7	93.2	77.2	82.3	83.0	89.4	70.9	79.4	73.3	80.6	71.5	78.8
40-49	45.3	87.8	33.7	76.8	39.5	84.5	37.2	73.4	34.8	69.1	28.0	71.1
30-39	29.9	78.8	21.9	69.1	20.5	74.2	21.7	59.9	20.0	58.4	14.6	61.6
18-29	22.7	75.2	17.5	65.7	16.1	60.1	14.7	55.2	13.7	53.1	12.1	51.5
18+	64.2	88.2	33.1	72.1	39.8	76.5	34.0	66.4	37.8	66.5	31.5	65.9

Figure 19 below shows vaccination uptake for 2nd dose over time by ethnic group and age group between the 8th of December 2020 and the 24th August 2021. The trends over time reflect the JCVI priorities for vaccination. For those aged 18 to 29 not all will be eligible for their second dose yet (i.e. 8 weeks since first dose), therefore the trend for this group is still increasing. For all other age groups there is a point at which uptake naturally plateaus as most people who want to get the vaccine when invited within their priority group have done so. As for dose 1, from that point onwards, there has been a continual decrease in the gap between the ethnic groups, particularly for African ethnic groups, which is indicative of some individuals in this group coming forward later (see Figure 19 and Table 21).

1

[1] Public Health Scotland COVID-19 Statistical Report As at 30 August 2021 Publication date: 01 September 2021 Pg. 52 – accessed here https://publichealthscotland.scot/media/8946/21-09-01-covid19-publication_report.pdf

- ✓ Vaccination uptake between March – September 2021 increased most significantly in the African, Caribbean and Black groups from 34% to 66%[2]

Challenges

- ✓ Ethnicity data was not collected at point of vaccination until October 2021. This has made it challenging to track real-time uptake of 1rst, 2nd, 3rd doses of vaccination and respond accordingly.

- ✓ Where data is available Public Health Scotland aggregate ethnicity data into racial classifications such as White, Black, Asian etc… This method of aggregation obscures the reality of uptake in real life. For example, while 90% of 'White' people are reported as haven received the vaccine once that data is dissagregate it indicates significant lack of uptake in the Polish ethnic group <50%.

- ✓ If peoples main concern is looking after their family, providing food and emotional support then engaging with the vaccination process is deprioritised. This is particularly true for those who have had negative interactions with the state such as those subjected to No Recourse to Public Funds.

- ✓ Fake news about all aspects of vaccination, content, process, side effects, long term consequences continues to disrupt uptake. Malicious content is routinely shared on social media and private messaging platforms beyond the vision of those sharing credible information. It is only at the point of attempting to increase informed consent that members and colleagues have become aware of the nature of some of the anti-vaccination content being shared.

- ✓ There are indications of vaccination fatigue. Uptake is highest on 1rst dose then decreases at 2nd and 3rd doses.

[2] https://publichealthscotland.scot/publications/covid-19-statistical-report/covid-19-statistical-report-1-september-2021/

Moving Forward

- ✓ Health and ethnicity data must be gathered and disaggregated as a core responsibility and function to inform policy and decision making

- ✓ In August 2022 BEMIS and the African, Caribbean and Black Inclusive Vaccinations subgroup of the Ethnic Minority National Resilience Network will co-launch bespoke research into minority ethnic vaccination experience with the Scottish Government and Cabinet Secretary for Health Humza Yousaf

- ✓ Learning on multiple methods of information access and sharing should be integrated into future vaccination and health campaigns

- ✓ As Scotland's ethnic diversity increases our health services will need to evolve to respond to changing access needs. The Vaccination programme has indicated that not all people approach health services in the same way. Access to mental health support has been particularly challenging for those for whom English is not their first language.

What did the February 2021 Survey Research indicate?

BEMIS were informed that while the vaccination programme was well known concerns remained about its development, implementation, and outcomes.

These included:

- Vaccines have not been tested on a diverse enough population
- They have tested different vaccines on Black and White people
- They are giving different vaccines to Black and White people
- If I go for the vaccine I might be deported
- The Vaccine has serious side affects
- What are the ingredients of the vaccine?
- Pressure of lockdown / pandemic is increasing mental health challenges and expansion of destitution this has an impact on people engaging with other services. Vaccination de-prioritised.

To respond to these issues our members and networks recommended to increase informed consent we must deploy,

- Trusted local partners should be used to help share information.
- Some events, like online Q&As with health professionals or meetings about vaccination must have capacity to be held in mother tongue languages.
- Not everyone accesses written information. For some people videos and visuals are better. These assets should also be available in different languages.
- Some of the translations of vaccine information use overly complicated language.
- Some questions affect all minority ethnic communities. What is in the vaccine? Is it safe? What are the side effects? However, there are also specific issues for Asylum seekers, multi-generational minority ethnic groups, newer migrant individuals and communities, and African and Black communities. Socio-economic status
- Provide multilingual mental health support
- Provide financial support to those in extreme poverty

Thus, in February 2021 the Scottish Government Race Equality Unit supported BEMIS with an initial grant support of £50,000 to facilitate the Vaccine Information Fund.

A further £40,000 was provided to support this work in March 2021.

Financial Summary

- Vaccine
  - 45 Groups funded £41,589.20

- Sustenance Fund £15,200.00
  – 7 groups funded –
  -173 Families and approx. 490 people

- Isolation, Recovery & Mental Health £23,010.00
  – we have over 120 diverse women families being supported and ongoing.

- Research £3,500.00
  - COVID-19 vaccine experience and hesitancy within African, Caribbean and Black (ACB) communities in Scotland

- Management fees - £5,750.00

Total £89,049.20

Impact Summary

- ✓ £41,589.20 was provided to 45 organisations to conduct VIF events
- ✓ Reach of 55,000 individuals

- ✓ 51 specific ethnic groups supported
- ✓ £15,200 was provided to 7 organisations to respond to destitution due to OMICRON impacts
- ✓ 200+ families supported due to OMICRON impact
- ✓ £3,000 was provided to the African, Caribbean, and Black (ACB) Subgroup of the Ethnic Minority National Resilience Network to commission research into ACB vaccine experience and journey
- ✓ Research to be launched with Cab Sec for Health August 2022 to inform future vaccination programmes
- ✓ £23,010 was provided too two women's organisations to provide bespoke multilingual mental health support
- ✓ Over 120 women receiving ongoing culturally sensitive and bi-lingual mental health support

Vaccine Information Fund

Funded Organisations

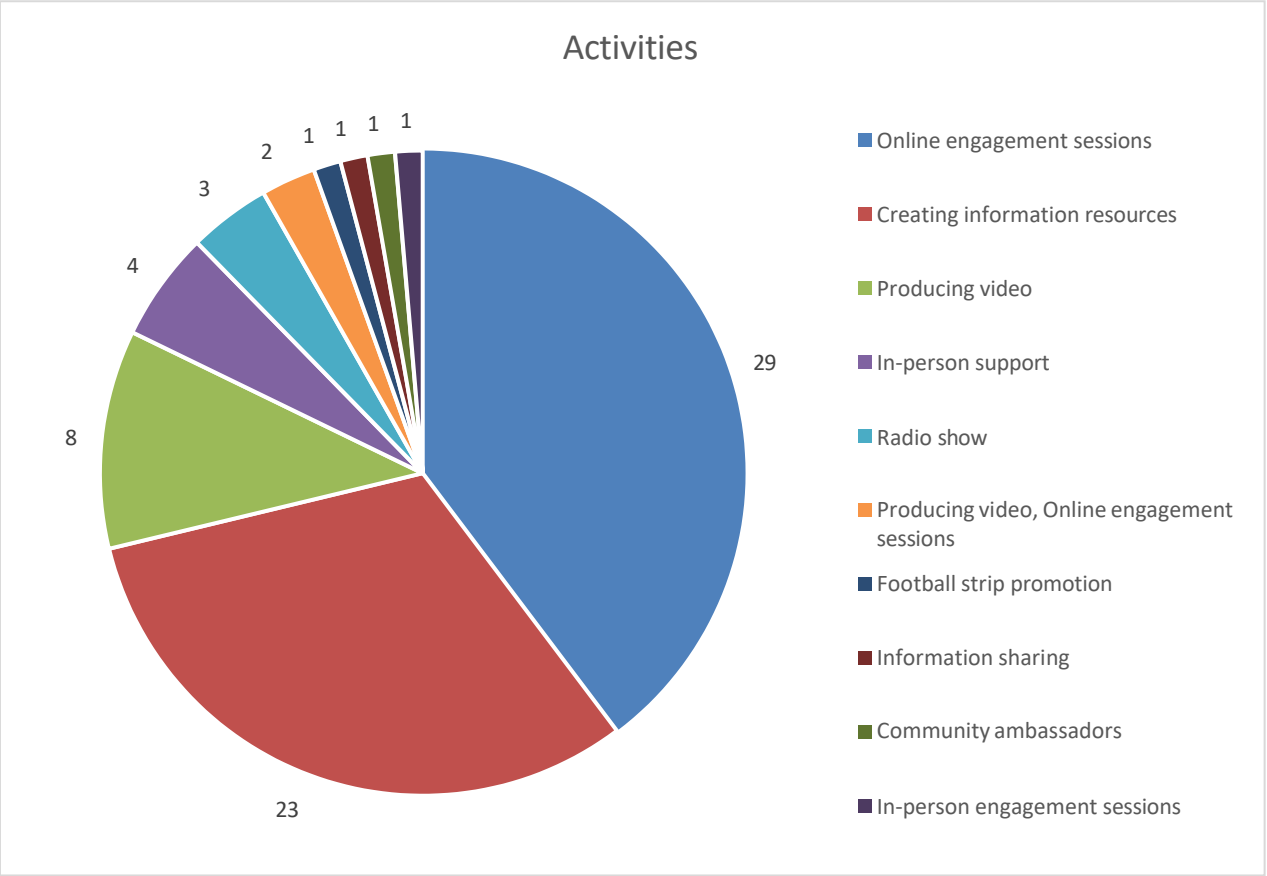
ORGANISATION	LOCATION	AMOUNT AWARDED
Ahl Al Bait Society	Glasgow	£450.00
B.J.O. Amara Association	Glasgow	£650.00
Cambria AFC	Glasgow	£1,435.00
Chabad of Edinburgh	Edinburgh	£1,000.00
Dumfries and Galloway Multicultural Association	Dumfries and Galloway	£1,000.00
East and Southeast Asian Scotland	Edinburgh and Glasgow	£1,000.00
Edinburgh Interfaith Association	Edinburgh	£480.00
Edinburgh Tamil Sangam	Edinburgh	£800.00
FENIKS	Edinburgh	£1,000.00
Fife Migrants Forum	Fife	£960.00

Freedom from Torture	Glasgow	£1,000.00
Friends of Romano Lav	Glasgow	£1,000.00
Fun Little Poland	West Lothian	£750.00
Glasgow Disability Alliance	Glasgow	£1,500.00
Govan Community Project	Glasgow	£1,000.00
HSTAR Scotland SCIO	Stirling	£1,400.00
Hwupenyu Health and Wellbeing Project	Glasgow	£450.00
Information and Learning for All Project (ILFA Project)	Glasgow	£900.00
International Women's Group	Glasgow	£1,000.00
Isaro Community Initiative	Glasgow	£970.00
Jambo! Radio	Glasgow	£1,875.00
LGBT Unity Glasgow/Scotland	Glasgow	£1,600.00
Milan Senior Welfare Organisation	Edinburgh	£1,000.00
Mossvale Community Church	Paisley	£1,000.00
Nepalese Himalayan Association Scotland	Aberdeen	£700.00
Networking Key Services Ltd.	Edinburgh	£1,000.00
Nigerian Muslim Community Scotland	Glasgow	£690.00
Organisation for Nepalese Culture and Welfare	Aberdeen	£1,000.00

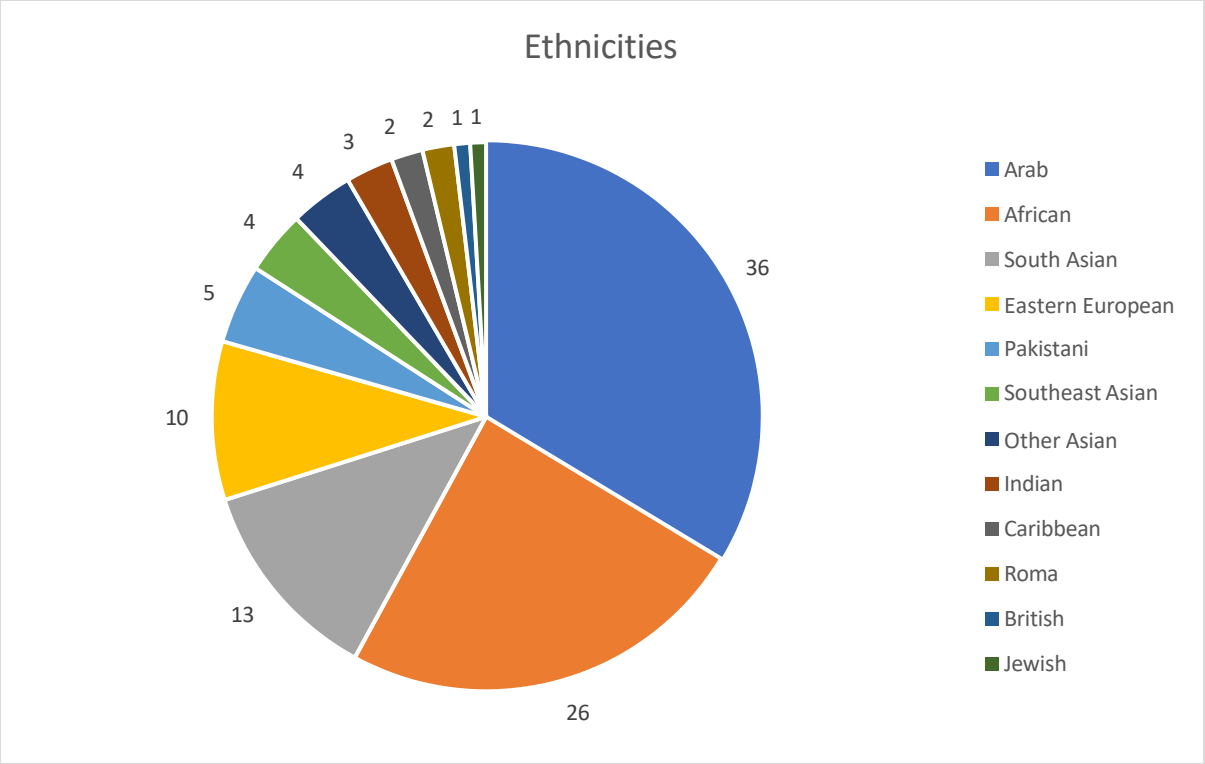
Pollokshields Development Agency	Glasgow	£880.00
Povestry Democratic Citizenship Association	Glasgow	£1,050.00
Raith Rovers Community Foundation	Fife	£500.00
Renfrewshire Effort to Empower Minorities (REEM)	Paisley	£1,000.00
SCOREscotland	Edinburgh	£998.00
Scottish Ethnic Minority Deaf Club	Glasgow	£700.00
Sharpen Her: the African Women's Network	Glasgow	£1,000.00
Sikh Sanjog	Edinburgh	£1,000.00
Sikhs in Scotland	Glasgow	£900.00
Somali Association in Glasgow	Glasgow	£800.00
Waverley Care	Glasgow	£1,200.00
West of Scotland Regional Equality Council	Glasgow	£990.20
Women In Action	Glasgow	£1,000.00
Youth Community Support Agency	Glasgow	£961.00
	TOTAL	**£ 41,589.20**

Location

Location base	Funded Applications
Glasgow	27
Edinburgh	8
Paisley	2
Aberdeen	2
Fife	2
West Lothian	1
Stirling	1
Edinburgh and Glasgow	1
Dumfries and Galloway	1
Grand Total	**45**



Ethnicities - 51 different ethnicities reported



Row Labels	Count of Application
Arab	
Iranian	4
Syrian	4
Iraqi	3
Arab	3
Kuwaiti	3
Yemeni	2
Saudi Arabian	2
Algerian	2
Middle Eastern	2
Libyan	2
Lebanese	1
Egyptian	1
Kurdish	1
Moroccan	1
Sudanese	1
Omani	1
Jordanian	1
Palestinian	1
Qatari	1
African	
African	15
Nigerian	3
Black	2

Namibian	1
Sierra-Leonian	1
Gambian	1
Somali	1
Kenyan	1
Mauritian	1
South Asian	
South Asian	4
Bangladeshi	3
Sri Lankan	2
Afghan	2
Nepalese	2
Eastern European	
Polish	4
Romanian	2
Eastern European	2
Albanian	1
Bulgarian	1
Pakistani	
Pakistani	5
Southeast Asian	
Vietnamese	2
Philippines	1
Southeast Asian	1
Other Asian	
Singaporean	1
Malaysian	1
Asian	1
East Asian	1
Indian	
Indian	3
Caribbean	
Caribbean	2
Roma	
Roma	2
British	
Scottish	1
Jewish	
Jewish	1

Mitigating OMICRON Impacts December 21 – March 22

Sustenance Fund December 2021 – March 2022

Organisation Name	Amount Awarded	People Supported
Crookston Community Group	£2,000.00	36 families – est. 100 people
CSREC Central Equality	£2,000.00	53 families – 192 people
Dumfries and Galloway Multicultural Association	£2,000.00	50 families – est. 150 people
Highland Migrant and Refugee Advocacy (HiMRA)	£2,000.00	16 families – est. 50 people
HSTAR Scotland	£2,500.00	16 families – 58 people
International Women's Group	£2,500.00	13 families – 61 people
Women In Action	£2,200.00	20 families – 61 people

Mental Health Support - December 2021 – March 2022

Organisation Name	Amount Awarded	Referrals
International Women's Group	£7,000.00	120 women ongoing
Women in Action	£3,010.00	25 women ongoing

ANNEX A – NOTE OF MEETING OF THE EMNRN 9TH DECEMBER 2020

ETHNIC MINORITY
NATIONAL RESILIENCE NETWORK

EMNRN Meeting 9th December 2020

10am – 12:15pm

AGENDA

Chairperson: Danny Boyle (BEMIS /EMNRN)

Scottish Government / Meeting Participants	
Julie Hoey	Covid Vaccine Policy Team Leader - Vaccines Division
Nuala Healy	Organisational Lead for Screening and Immunisation – Public Health Scotland
Ben Macpherson	Minister for Public Finance and Migration
Martin Hayward	Equalities and Human Rights Commission

Item	Time
Zoom meeting open. Participants sign in with music theme as we await attendees and opening	**9:45 – 10:00**
Welcome Tanveer Parnez / Danny Boyle – Thanks and Agenda	**10:00 – 10:05**
Message to the EMNRN from **Christina McKelvie MSP** – Minister for Older People and Equalities	**10:05 - 10:10**
Updates from Thematic subgroup meetings – Group Chairpersons	**10:10 – 10:30** 1) Mental Health – Fiona Crombie 2) Data, Health and Social Outcomes – Jenni Keenan 3) BME frontline workers and Economic Recovery – Charmaine Blaize 4) Education and YP – Vicky Wan 5) Collaboration – Nina Munday

	6) Inclusive Health Messaging – Suzanne Munday
Julie Hoey and Nuala Healy – Scotland's Vaccination Plan	**10:30 – 11:30**
Ben Macpherson Minister for Public Finance and Migration	**11:30 – 12:00**
Martin Hayward: Commission Inquiry into the experience of low paid ethnic minority workers in Health and Adult Social Care and opportunities for people and organisations to contribute to this over the next months.	**12:00 – 12:05**
Summary and Next Steps	**12:05 – 12:15**

Attendees

NAME	ORGANISATION
Danny Boyle	BEMIS Scotland
Tanveer Parnez	BEMIS Scotland
Martin Fotheringham	CSREC
Harriette Campbell	African Caribbean Women's Association
Alan Gray	Forth Valley Migrant Support Network
Martin Hayward	Equality and Human Rights Commission
CHRISTINE MEMBI	The Hope Project
Maryam Wasim	Scottish Pakistani Community Recovery Network
Kimi Jolly	East and South East Asian Scotland
Margaret Lance	Women in Action
Trishna Singh	Sikh Sanjog
Jenni Keenan	PKAVS Minorities Community Hub
Michelle Ritchie	Police Scotland
Shubhanna Hussain-Ahmed	Coalition of Carers in Scotland
Charmaine Blaize	UNISON Black Workers Committee
Clare Daly	Highland Birchwood Centre HIMRA
Sarah Kwan	East and South East Asians Scotland
Melanie Weldon	Scottish Government (Health Improvement)
Micheline Brannan	Convenor BEMIS
Rukhsana	MILAN senior welfare
Unyimeobong Matthews	Inspiring Families

Ahashan Habib	Aberdeen Multicultural Centre
Billy Lynch	Fife Migrants Forum
Soumi Dey	Education academic
Ephraim Borowski	SCoJEC
Fiona Crombie	Freedom from Torture
Nuala Healy	Public Health Scotland
Susan Barnes	BEMIS Scotland
Dr. Raj Bhopal	SHELS / Expert Reference Group
Fariha Thomas YCSA	YCSA
Davie Donaldson	Progress in Dialogue
Nina Munday	Fife Centre for Equalities
Julie Hoey	Scottish Government Vaccination Team Leader
Aqeel Ahmed	Scottish Government Race Equality Policy Manager
Hilary Third	Scottish Government Race Equality Team Leader
Victoria Lopez	Scottish Government marketing
Asma Abdallah	Empower Women for Change
Yen Nalci	Dumfries and Galloway Multicultural Centre
Olivia	Poverty Alliance
Shasta Ali	Corra Foundation
Charlie Goodwin-Smith	Scottish Government
Elizabeth Oldcorn	Public Health Scotland
Yaa Nipaa	Hwupenyu Project
Catherine McGee	Refugee Survival Trust
Ian Sirrell	Scottish Government Culture, Tourism and Major Events
Ben Macpherson MSP	Minister for Public Finance and Migration
Richard Walsh	Scottish Government Culture, Tourism and Major Events

Meeting Note:

- **Tanveer Parnez** (BEMIS) welcomed all attendees to the final meeting of the network in 2020. Thanked everyone for their hard work and commitment in difficult circumstances. That the vaccine offers hope for 2021 and that BEMIS remain committed to working with and supporting communities as we move forward.

- Welcome from the Minister for Older People and Equalities, Christina McKelvie MSP

Video Link: https://www.youtube.com/watch?v=w24qm5lBOWE

- **Updates from Subgroups**

1) **Mental Health**

- Group meeting with Scottish Government officials to discuss opportunities for mental health provision of minority ethnic communities in Governments plans
- Group will continue in 2021 to engage with relevant stakeholders to ensure that minority ethnic mental health welfare is informed and responsive to diverse needs.

2) Data, Health and Social Outcomes

- Group pleased to learn that Minister McKelvie has written to the group to outline the Scottish Governments commitment to recognising all of the ethnic diversity of Scotland
- The group will work with the National Records of Scotland in 2021 to ensure that the Census 2022 has the ability to reflect accurately the minority ethnic population of Scotland

3) BME Frontline Workers

- Group FOI'd 14 health boards to ascertain the ethnic diversity of staff. The number of staff who have received individual CV19 risk assessments. 10 Received thus far and working through responses. Early data suggests NHS staff diversity is higher than the population diversity as a whole based upon 2011 census. This is to be celebrated.
- UNISON Black Workers Ctte have done significant employee canvassing and research to identify concerns of racialisation and racism in the workplace. In addition there is a lack of BME senior staff. Both of these issues will be priorities for 2021 and the REAP 21-25.

4) Education, Children and Young People

Priorities for 2021, as requested by REU.

- Supporting voices of EM CYP in policy development and service design (continue to be a strong key theme)
- Curriculum reform, given the process will continue for some time
- Rights to accessing services including language support (aligning with UNCRC)

5) Collaboration

- Group focussed on policy issues continuing throughout CV19 such as hate crime and funding.
- Followed up engagement with SG officials and Police on hate crime.
- Groups learned more about each other's work across the year.
- Group will be amalgamated into other groups moving forward.

6) Inclusive Health Messaging

- New group set up in late 2020 to respond to challenges in getting clear, accurate and concise heath messaging to diverse communities
- Group will have a strategic focus on vaccination and other health communication in 2021
- MECOPP leading who have significant experience in inclusive health messaging and translation during the pandemic.

Julie Hoey and Nuala Healy – Scotland's Vaccination Plan

- prioritisation of groups to gets the vaccine first (JCVI Priority groups for coronavirus (COVID-19) vaccination: advice from the JCVI, 2 December 2020 - GOV.UK (www.gov.uk), including the specific issue of why minority ethnic communities have not been singled out for prioritisation at this stage

- the vaccines: Pfizer, Oxford AstraZeneca, others in the pipeline; ongoing trials in UK and calls for volunteers, specifically from minority ethnic communities; vaccine ingredients

- plans for roll out – started vaccination in Scotland on 8/12; how long will it take?

- Informed consent – allowing people to ask questions about vaccines and vaccination – what we're doing to provide that information and what you can do to share it

- Maximising take up – significant uptake of an effective vaccine can lead to collective immunity; what are we doing to maximise uptake and what else should we consider? How can you help? What are the likely barriers and how will we work together to overcome them?

- Resources: https://www.publichealthscotland.scot/downloads/healthcare-worker-covid-19-resourceslt

- https://www.publichealthscotland.scot/downloads/healthcare-worker-covid-19-resources

Responses:

Scottish Pakistani Support Network (SPSN):

- How long does the vaccine take to work?
- What are the side effects if any?
- What are the implications of those who choose not to take the vaccination?
- How did the reference group engage all BAME communities?

- Were community and faith leaders engaged?
- When we book the Covid19 test at the Gov.uk website, we are allowed to select our ethnic background, for example Pakistani, why is data collected and analysed as general BAME groupings?
- Why in Scotland do we not adhere to the 14 ethnic categories under the Equality Act 2010?
- Is there any will to commit to positive action for specific BAME communities like the Pakistani communities who have been disproportionately impacted by Covid19?

SPCN Communication:[3]

- Need more audio/visual messages in different community languages as opposed to just translated literature which is not helpful if people are not able to read those language or able to use digital learning.
- Need more information on myth busting and misconceptions in different languages, again audio /visual preferrable.
- The average Pakistani person in Scotland speaks more Punjabi than Urdu if there is a choice given between the two.
- The Urdu used is far too high level , jargon based and aimed at those who are educated in the Pakistani community. Not understood by many people. It needs to be toned down a bit to more simple language.
- Translate into easy read/plain English then translate to Urdu, Punjabi is normally spoken and not read in Pakistani community. Any document produced in Urdu also needs to be a maximum of two sides of A4 paper.

Dr. Raj Bhopal (SHELS and Expert Reference Group:

- Vaccine welcome news but CV19 will remain a long-term issue with economic, social recovery.
- Information about why we get vaccinated, content of vaccine and consent are critical to a successful and credible strategic administration.
- Should Scottish SIMD index play a role in prioritising vaccinations?

Davie Donaldson – Progress in Dialogue:

- We are hearing many conspiracies around the vaccine, notably worries that it includes foetal cells etc.
- This is causing much grassroots distress and is adding a religious element to not getting the vaccine (among Roma and Traveller communities).
- Is there are any official resources disputing claims such as these that we can share. Majority of the communities we support are refusing to accept the vaccine when it comes.

[3] *Please note communication feedback has been given by community members, network members, third sector BAME Health workers, and media and comms agencies and professionals*

Jenni Keenan – Perth and Kinross Minorities Communities Hub:

- Older people from minority communities, and EE communities, where literacies can be low in English and native languages and access to uk media channels and info sharing is very low. There is crossover with the most sceptical individuals here, which adds a layer of complexity.

Trishna Singh (Sikh Sanjog)

- We need to remain aware of the differing dialects of spoken Punjabi for Sikhs and for Pakistani community there are similarities, but they are differences that can affect the whole message.
- It remains a source of significant concern and frustration that the needs of diverse communities are still not appropriately integrated into the response of Government and others. Our communities have been here for decades and still we are being asked after the problem has happened to help fix it. At such a critical time this is unacceptable. This makes us feel like we are not part of the Scottish community. Until the power structures are changed and our needs are fully integrated into Scottish policy as a norm then our rights will continue not to be equally responded to.

Danny Boyle (BEMIS)

- In relation to vaccine prioritisation the network has been aware since March of what we have termed the informal frontline. Not healthcare workers but school teachers, taxi drivers, shop owners, retail workers, construction workers and other employment sectors that remain open and expose those workers to higher risks not reflected in vaccine prioritisation. Some of these sectors employ disproportionate numbers of ethnic minorities who also happen to live in overcrowding or high-risk SIMD areas. A hypothetical example is the Pakistani taxi driver, living in overcrowding. Is there a case to be explored that there should be an equalities targeting strategy for vaccine roll-out given the higher number of Pakistani male deaths? Should JCVI priority groups include

    - ✓ Employment
    - ✓ Ethnic disparity
    - ✓ Socio-economic status
    - ✓ Housing

Members thanks Julie and Nuala for their participation and wished them every success in their work. Agreement to use network to continue dialogue and follow up via national and subgroup data and health and inclusive health messaging.

Minister for Public Finance and Migration Ben Macpherson MSP

- Thanked members for their hard work diligence and commitment to responding to CV19 across Scotland.
- Outlined that Scotland remains committed to being an open and welcoming nation that cherishes the economic, social, and cultural impact of European and International migrants
- Minister encouraged communities to embrace and participate within the Scottish Winter Festivals period
- Highlighted that on the 25th of January Burns night will take place and offer communities the opportunity to start the new year positively to celebrate in different multicultural ways.

Open floor for members to respond to Minister and General ask – what do we want for 2021?

- Members expressed their thanks to the Minister for his attendance and participation over the year.
- Members also outlined that to have a truly representative Scotland we must have more diversity in the Parliament. Especially from significantly underrepresented communities. There remains a lack of people of colour, women, and other ethnic and national groups.
- General comments followed on the difficulties posed by 2020 and the requirement for the EMNRN to have been instigated. Members found the network invaluable and a safe place in a very difficult year. There is an appetite to maintain its structure in 2021.

Martin Hayward Equalities and Human Rights Commission

- The Commission has launched Inquiry into racial inequality in health and social care workplaces.
- We want to understand the experiences of ethnic minority people working on the frontline in lower-paid roles, particularly during the COVID-19 pandemic.
- Based on the evidence we find, we will make recommendations aimed at employers, governments and other agencies to improve conditions for ethnic minority workers.

Link to submit evidence and further information can be found here:

https://www.equalityhumanrights.com/en/inquiries-and-investigations/inquiry-racial-inequality-health-and-social-care-workplaces?utm_source=e-shot&utm_medium=email&utm_campaign=RaceInquiryCallForEvidence

- Martin thanked Charmaine Blaize of the Unison Black Workers Committee for her support and expertise already in helping to inform the inquiry.

Convenor of BEMIS Micheline Brannan

- On behalf of BEMIS, Micheline thanked all members and attendees for their commitment over the year. That our work together had been inspirational and that when we see communities work so closely together, we are stronger.
- Thanked BEMIS board members for their continued participation and support of staff and the network.
- That we should continue to deploy the beneficial aspects of technology we learned in 2020 through the use of platforms like zoom we can have 50-60 people together who otherwise may not be able to travel to a location.
- Acknowledged the diligence and commitment of various civil servants from different departments who have attended and responded to the network over 2020
- Micheline acknowledged the support of the Scottish Government Cabinet Secretary Aileen Campbell and Ministers Ms Christina McKelvie and Ben Macpherson for their continued support of the network.
- Finally thanked Rami, Tanveer, Sue, Neil and Danny for their hard-work over 2020 in challenging circumstances.

Meeting Ends: 12:17

ANNEX B – Briefing to the Scot Gov Inclusive Vaccinations Group March 2021

Ensuring Equal Access to vaccination information for Scotland's minority ethnic communities - BEMIS Scotland interim report to - COVID-19 Vaccine: Inclusive Programme Steering Group. 16/03/2021

Vaccination and the Equality Act 2010

- The provision of vaccination information, access and administration fall within the scope of the provisions of the Equality Act 2010 and the delivery of a public function.

- Thus, in respect of the vaccination plan duty bearers are obliged to ensure that citizens acknowledged by the protected Racial provisions of Colour, Nationality, ethnic or national origin have access too vaccination information and administration in a way that is compliant with their human rights.

- In Scotland this may mean taking a tailored approach to specific ethnic groups.

- Minority ethnic communities in Scotland are no different insofar as they have the same human concerns as any other community however some challenges are unique to them and we must respond to these.

- In addition, at the time of a public health crisis in the provision of public health information or administration of vaccines citizens restricted by punitive immigration designations such as undocumented migrants, Asylum seekers or those affected by EU Exit fall within the scope of the Equality Act as opposed to their immigration or lack of status.

- By virtue of this legal entanglement and experience with other official departments that have been hostile to their existence in the UK / Scotland some of these communities and individuals are harder to reach. In this respect, trusted, local partners and community contacts are critical to ensuring they have the same access to information as the rest of the population.

- The Vaccine Information Fund aims in part to help bridge this gap and inform key stakeholders of issues and methods of delivery that can be derived from this direct community intelligence.

What our 12 months of pandemic response told us about the vaccine programme?

As Scotland moves through its vaccination programme, it is crucial that all the people of Scotland have informed and equal access to information about the vaccine.

Through the evidence developed as BEMIS Scotland & the Ethnic Minority National Resilience Network (March 2020 – Present) and our Health and Vaccination Survey, we know that not all individuals and communities have or are able to access information in the same way.

In relation to Scotland's minority ethnic communities and increasing access to relevant and responsive information regarding the vaccination, we are informed that:

- Trusted local partners should be used to help share information.
- Some events, like online Q&As with health professionals or meetings about vaccination must have capacity to be held in mother tongue languages.
- Not everyone accesses written information. For some people videos and visuals are better. These assets should also be available in different languages.
- Some of the translations of vaccine information use overly complicated language.
- Some questions affect all minority ethnic communities. What is in the vaccine? Is it safe? What are the side effects? However, there are also specific issues for Asylum seekers, multi-generational minority ethnic groups, newer migrant individuals and communities, and African and Black communities. Socio-economic status

As such, as part of the Scottish Government efforts to ensure equal access to information regarding the Vaccines, BEMIS Scotland are commencing a Vaccine Information Fund programme to empower communities to have engagement sessions about the vaccine programme and develop information assets that can be used to increase informed consent.

Sample community events ongoing as of 16/03

Account Name	Location	Target
Jambo! Radio	Glasgow	African communities
Govan Community Project	Glasgow	Various, including asylum and refugee groups
Freedom from Torture	Glasgow	Multiple ethnic groups including asylum and refugee groups
Isaro Community Initiative	Clydebank, Glasgow	Multiple ethnic groups
Networking Key Services Ltd.	Edinburgh	Bangladeshi / Pakistani multi generational
Fife Migrants Forum	Fife	Multiple predominantly easter European
Ahl Al Bait Society	Glasgow	Arab speaking communities including asylum seeking individuals

Pollokshields Development Agency	Glasgow	Multi-generational Pakistani / Muslim groups
Dumfries and Galloway Multicultural Association	Dumfries and Galloway	Multiple ethnic groups including refugee community
Organisation for Nepalese Culture and Welfare	Aberdeen	Nepalese community and others in Aberdeen

Written evidence submitted by Health and Social Care Alliance Scotland

Health and Social Care Alliance Scotland (the ALLIANCE)

COVID-19 Recovery Committee - COVID-19: communication of public health information

June 2022

Introduction

The Health and Social Care Alliance Scotland (the ALLIANCE) welcomes the opportunity to respond to the COVID-19 Recovery Committee's inquiry into 'COVID-19: communication of public health information'.[i] The ALLIANCE is a national third sector intermediary for health and social care with over 3,000 members including third sector health and social care organisations, disabled people, people living with long term conditions, and unpaid carers.

The ALLIANCE has been asked to provide evidence on the following:

> "To consider whether public health information about COVID-19 is accessible and meets the needs of specific audiences going forward, including people in the shielding category and communities where there has been below average uptake in vaccination to date."

Public health messaging during COVID-19

The ALLIANCE's 'People at the Centre' engagement programme captured the lived health and wellbeing experience of a broad range of people living in Scotland during the COVID-19 pandemic.[ii] ALLIANCE members shared that public health messaging has been variable, both at national and local levels.[iii] Whilst some people found government guidelines useful, many others found the changing guidelines and availability in services difficult to follow, leading to confusion and a lack of clarity around guidance.

This has been repeated consistently by ALLIANCE members and partners, and continues to be an issue in relation to the current state of the pandemic, with a direct impact on people's health and wellbeing and their ability access health and social care services throughout COVID-19.

A lack of person-centred communication

People have shared that there has been a lack of tailored and person centred communication during the COVID-19 pandemic. People have reported receiving blanket information provision, which is too general, ambiguous and does not consider the needs of different population groups, including people at high clinical risk, disabled people, people living with long term conditions, and unpaid carers.[iv]

Many people have reported feeling that their rights and needs have been overlooked throughout COVID-19 due to a lack of accessible information. There has been a lack of COVID-19 information in a range of accessible formats including British Sign Language (BSL), alternative languages, or community languages such as Braille, Moon, or Easy Read. As a result, people were often not fully informed on a universal and equitable basis. This raises key concerns about people who experience communication or language barriers being indirectly discriminated against.

ALLIANCE members have also raised specific issues with confusing, inaccessible, and contradictory communication for autistic adults. For example, a reliance on telephone communication in GP practices is often inaccessible for autistic people, and written communication can be too ambiguous, lacking clarity on key information. A lack of tailored, person centred approaches throughout health and social care interactions mean that processes are often overwhelming and stressful for individuals and their families.

Absence of messaging

At the outset of COVID-19, many services adapted or redesigned due to physical distancing restrictions. Communication to explain changes to health and social care was often lacking, which left many people facing uncertainty. For example, people reported having social care packages reduced or withdrawn completely with little or no notice.[v]

Further, as restrictions to respond to the virus have been reduced, many people who were on the shielding list and who are at high clinical risk have indicated that there has been a complete lack of public health communication. As a result, many people are receiving information from online platforms and undertaking their own research to inform their decision to continue to shield.

Lack of transparency

There is a lack of transparency around decision making in relation to COVID-19. This has a particular impact on people who are at high clinical risk, and for unpaid carers. It is not clear how decisions are being made, whether impact assessments have been undertaken to inform decision making and embed equalities and human rights principles, what monitoring processes are being used to review decisions, and whether decisions have been subject to consultation with people with lived experience.

People in the shielding category and at high clinical risk

Many people at high clinical risk are continuing to shield, and have been in permanent lockdown since March 2022. ALLIANCE members and partners have shared that people at high clinical risk feel that public health messaging has been absent, particularly since restrictions have reduced. People have reported experiencing feelings of abandonment, and a lack of consideration of their rights and needs as we enter the ‘recovery’ stage of the pandemic.

It has been noted that fear of COVID-19 infection is still very real for people at high clinical risk and for unpaid carers. People are continuing to wear masks, test regularly, and limit contact with friends and family. The impact on people at high clinical risk and unpaid carers is profound; people are experiencing isolation as they

continue to isolate from friends and family and feel more at risk as measures taken to protect people from the virus have been reduced.

It has also been noted that the public health messaging around COVID-19 can be very polarising, with a focus on 'before' and 'after' lockdown and restrictions. This polarisation is also reflected in media reports, which has a direct impact on wider societal attitudes towards the virus.

Long Covid

There is a lack of understanding of the risks of COVID-19 infection, and the scale and severity of Long Covid. Efforts are needed to improve understanding and knowledge of Long Covid in the community. In research commissioned by the ALLIANCE, 'Accessing social support for Long Covid', issues with public awareness about Long Covid and the effect it can have on people were highlighted.[vi] The report recommended that the Scottish Government should run a national Long Covid communications campaign to educate the public about Long Covid and the effect it can have on people, and highlight key resources and supports.[vii] Key themes should include supportive employment practices, information about social security and social care, and educational best practice.

We also know that there is a lack of communication around the risks of Long Covid for children and young people. Further research and engagement is needed in this area to fill the knowledge gap, and to raise awareness with the public, including parents and carers.

Sensory loss

COVID-19 has exacerbated and compounded many pre-existing communication barriers for people living with sensory loss, as well as introducing new barriers. Some of the key issues are summarised below:

- There was a lack of consideration of how blind or deafblind people would be able to follow distancing measures. Additionally, the combination of face masks, screens and social distancing has had a significant impact on deaf people. These include challenges in lip reading due to face masks; booking appointments online or accessing face to face appointments without a support worker; and navigating public spaces.[viii] ALLIANCE members reported that this also led to some people with sensory loss losing confidence when going outside.

- COVID-19 restrictions had a significant impact on tactile communication, with many tactile activities being stopped. A lack of positive communication can cause rapid deterioration of people's health and wellbeing.

- The introduction of new technologies have created specific challenges for people with sensory loss. For example, increased use of telephone based communication and video consulting at GP surgeries has created additional

communication barriers for deaf people, and people who are blind or deafblind have faced challenges using new apps such as the NHS Track and Trace app.

Value of the third sector

The important role of the third sector and community groups during COVID-19 has been highlighted consistently. There was a feeling that third sector organisations adapted to deliver services that statutory services were not willing to deliver, and a perception that third sector organisations were left to fill the 'gap', including in relation to public communication.

We know from speaking to our Community Links Workers that many people seek advice and support from Community Links Practitioners, with whom they often have well-established and trusting relationships. This is also true of many third sector and grassroots organisations, whose expertise and communication pathways should be included as part of a wider suite of community resources in communicating public health messaging around COVID-19. Community and grassroots organisations have been a key source of information provision during COVID-19 and overcoming trust barriers.

Examples of good practice during COVID-19

There have been examples of good practice in communication taking place throughout the pandemic. It is important that positive actions such as those outlined below are harnessed and maintained as we continue through the pandemic:

- **Proactive approach:** Some GPs reported that early on in the pandemic they were concerned that those people they usually had most contact with had not been in touch.[ix] Mechanisms were put in place to ensure contact was made. For example, one of the Deep End GP practices had their care coordinator team to check in with those people they were most concerned about to check that they were okay, had enough food, and were safe at home. Many people did not know that their GP surgery was still open and were happy to receive calls from people they knew and trusted. Similarly, some Health and Social Care Partnerships (HSCPs) had staff reach out proactively to people on shielding lists who had not responded to telephone or text communications by door knocking.

- **BSL interpretation:** During the COVID-19 pandemic, BSL interpretation became readily available for the First Minister's COVID-19 briefings. This was a welcome change for deaf people, and helped to ensure people from different population groups were informed on the virus on a daily basis.

- **Third sector initiatives:** The third sector has played a vital role in providing person centred support to communities, particularly in relation to Long Covid

information and support provision. For example, ALLIANCE members, Let's Get On With It Together (LGOWIT), have been working in partnership with NHS Highland to offer self management e-learning for people living with Long Covid.[x]

- **Digital services:** Digital services such as NHS Inform and ALISS (A Local Information System for Scotland) have provided information about a wide range of organisations, groups, services and activities throughout COVID-19.[xi] These are useful tools that have helped to communicate public health information as well as signposting people to find and connect with assets that exist in their local communities.

About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims; we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

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[i] The Scottish Parliament, 'COVID-19: communication of public health information'. Available at: https://www.parliament.scot/chamber-and-committees/committees/current-and-previous-committees/session-6-covid19-recovery-committee/business-items/covid-19-communication-of-public-health-informatiwon

[ii] The ALLIANCE, 'Health, Wellbeing and the COVID-19 Pandemic Final Report'. Available at: https://www.alliance-scotland.org.uk/blog/resources/health-wellbeing-and-the-covid-19-pandemic-final-report/

[iii] As above.

[iv] The ALLIANCE, 'ALLIANCE Briefing – COVID-19 Independent Inquiry'. Available at: https://www.alliance-scotland.org.uk/blog/resources/alliance-briefing-covid-19-independent-inquiry/

[v] As above.
[vi] The ALLIANCE, 'Accessing social support for Long Covid', p.45. (May 2022). Available at: https://www.alliance-scotland.org.uk/wp-content/uploads/2022/06/Long_Covid_report_final.pdf
[vii] As above.
[viii] The ALLIANCE, 'Health, Wellbeing and the COVID-19 Pandemic Final Report'. Available at: https://www.alliance-scotland.org.uk/blog/resources/health-wellbeing-and-the-covid-19-pandemic-final-report/
[ix] The ALLIANCE, 'Health, Wellbeing and the COVID-19 Pandemic Final Report'. Available at: https://www.alliance-scotland.org.uk/blog/resources/health-wellbeing-and-the-covid-19-pandemic-final-report/
[x] NHS Highland, 'Launch of Long COVID e-Learning Self-Management Resource'. (18 August 2021). Available at: https://www.nhshighland.scot.nhs.uk/News/Pages/LaunchofLongCOVIDeLearningSelfManagementResource.aspx.
[xi] NHS Inform, 'Coronavirus (COVID-19)'. Available at: https://www.nhsinform.scot/illnesses-and-conditions/infections-and-poisoning/coronavirus-covid-19/ ; ALISS. Available at: www.aliss.org

Written evidence submitted by Dr Sally Witcher OBE

Covid-19 Recovery Committee Inquiry: Communication of Public Health Information

Written evidence

In support of oral evidence session 23 June 2022

Dr Sally Witcher OBE

1. Introduction

This written evidence concerns the second aim of the Committee's Inquiry into the communication of public health information, namely: "whether public health information about COVID-19 is accessible to and meets the needs of specific audiences going forward, including people in the shielding category and communities where there has been below average uptake in vaccination to date"

It focuses primarily on communication with regard to people formerly on the Highest Clinical Risk List (HRL) formerly the shielding group/s. There is also much to say about the information needs concerning the growing number of people with Long Covid and of unpaid carers. These are groups for whom the consequences of pandemic mismanagement have been and remain directly acute, initially of Covid and, now that the tools to mitigate risks exist, of failures to use them effectively. They are the canaries in the mine. Yet, far from their lived experiences being a barometer for gauging the success of pandemic management, government strategy appears to be contingent on airbrushing them – and, indeed, the continuing pandemic – out of public view. Moreover, the rise in Long Covid should position it as a primary indicator, alongside hospitalisation and death rates.

This submission begins with strategic considerations and progresses to detail of communications to people with highest clinical risk. It is written in a personal capacity as someone who was on the Highest Risk list, who is ineligible for additional boosters or antivirals, who has worked in many senior roles (see annex for biographical note). Along with my own personal experience as a reluctant case study, it is informed by a Twitter thread I issued on 14 June (see annex), asking people with high clinical risk or Long Covid and unpaid carers what they would say to the Committee to inform their

inquiry. This is clearly not a scientific study, but it provides a compelling snapshot, and a damning verdict on government communication, misinformation, lack of information, the subsequent rise and perpetuation of disinformation, and the consequences. Of course, there may be other people in those groups who feel differently. However, there was a large response, including by direct message and email, and there is not space here to include all. Committee members may, though, find it helpful to read all the responses to the thread[1].

My evidence is also informed by my meetings and correspondence with officials and the Minister for Equalities. I am grateful to them for their willingness to engage with me, even though they have not answered most of my questions!

This submission can only convey a flavour of the ever-widening chasm between the loss of rights and freedoms for people with high underlying clinical and exposure risk, people with long Covid and unpaid carers, and those returning, or attempting to return, to a pre-Covid normal. A similar-sized directly-related chasm exists between what government communicates and the lived experiences of those groups.

2. Government messaging

Government messaging on Covid has long been that the pandemic is basically over and we are now in the process of recovery (even the name of this Committee reinforces that!). We are going back to normal now, so there is no longer any need for legal requirements to wear masks, isolate if infected or take any precautions. Recommended guidance suggests it would be a good idea, but it has been made harder to follow it, as in-person attendance is re-established as the default expectation, support for isolating is removed, charges for tests introduced and testing centres wound down. Some data is no longer collected or published. This makes it impossible for the public to understand the reality of what is happening, to gauge personal risk of exposure and exercise 'Covid Sense' (the current slogan) accordingly. As one person remarked: "Just because everyone's pretending it's over doesn't mean that covid 19 has gone and it could still kill or disable you and your family or cause liver failure in your child"

Inevitably, with the arrival now of a new highly transmissible variant, public health communications, often mixed, have descended into complete confusion. Over recent days we have been warned that a highly transmissible new variant is here, infections are rising, herd immunity is probably impossible, many will get ill, many won't shrug it off, 6 months after a booster people may not be adequately protected and experts recommend that the entire population should be offered a booster[2], and all this is bad for health,

[1] https://twitter.com/SalWitcher/status/1536637814883897345

[2] See, for example: https://www.heraldscotland.com/news/20206083.covid-scotland-expert-predicts-quite-surge-cases-coming-weeks/?ref=twtrec ;

disruption to the economy and education. We have also been told (in one case by the same expert) that omicron is mild, hardly anyone now is at high clinical risk, there's no need to panic or reimpose restrictions [protections][3]. It is illogical mixed messaging like this which is precisely what causes people to panic, lose trust and disengage. Meanwhile, the drivers behind government approach are far from self-evident. The adverse consequences for the economy[4], the protection of the NHS, and education, for lives and life-chances, are very clear. As one person put it "I'd ask how the economy and society can survive with ~1m working age adults leaving full time employment with (or caring for somebody with) LongCOVID. (These are ONS/CDC figures)". Another remarked: "The bank of England have noticed Long Covid, why haven't they?!"

People have a need to make sense of the world and their place within it; never more so than when their lives are profoundly adversely impacted and they are powerless to change it. To be repeatedly presented with an image of what you know to be untrue is to be 'gaslit'. People may respond with rage and/ or depression and detachment. Meanwhile, the need to believe the world is not as it is can drive social division and tribalism around competing framings. If lockdowns and isolation are bad for mental health, so too is all this. If government does not take a proactive, comprehensive and consistent approach to communicating how the dots join, people will do the joining from whatever scraps of information they can find, and/ or others will step into the void to join them up in ways that support their own agendas. Thus, what government public health communications omit to say can be just as (more?) important than what they do.

3. Gaps and limitations: Strategic understanding

Government communications will inevitably be a product of underlying strategic framing, the intended outcomes, driven by quality of data and understanding, political priorities and practicalities, as expressed via policies then translated into delivery. As is entirely to be expected, people do not draw neat distinctions between strategy, policy and communications, nor between clinical policy and public health policy, even though the latter is a meaningful distinction in this context. What they know of all these depends on what is communicated and how accessible it is. Communications are the visible tip of the iceberg.

One major gap concerns the need for equal emphasis and comprehensive embedding into strategy alongside clinical matters the fact that we now have

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https://www.theguardian.com/commentisfree/2022/jun/13/rise-covid-cases-what-we-know-so-far?CMP=fb_gu&utm_medium=Social&utm_source=Facebook&fbclid=IwAR0aQDEEmV8mpGqk6_a7yIB5NiXtxfRfp-K0ZoeIVynAQvP5geZxPNMQMkA#Echobox=1655104549 ;

[3] https://www.bbc.co.uk/news/uk-scotland-61769940

[4] See, for example: https://www.ippr.org/news-and-media/revealed-8bn-hit-to-uk-prosperity-as-long-covid-and-illness-drives-400-000-more-people-from-the-workforce

the tools to #BuildBackBetter and create a safe #InclusiveNewNormal[5]. 'Living with Covid', avoiding the generation of new dangerous variants requiring major restrictions on freedoms; avoiding a new normal of repeated infection and rising incidence of long-term disability (is that 'Build Back Better'?), means making intelligent use of those tools, not abandoning them. It means taking action on Clean Air to make environments safer, including investment in HEPA air filters that extract all manner of viruses and allergens, not just focusing on increasing individual clinical resilience, and with regard to that, making maximum use of the learning on treatment, as well as on the access advantages on-line, more effective FFP3 masks, etc. It also needs to be rights-based. That means there is a major policy and communications task, reminding people of wide-ranging existing laws and standards, updating them as necessary, and improving access to justice. Relevant laws and rights span equality, human rights, environmental health standards/ clean air, workplace health and safety, building regulations, inclusive economy, hate crime, access to justice, etc, etc.

This means thinking of pandemic management as requiring action across a wide range of Ministerial portfolios. It means factoring this into account in the current review of National Performance Outcomes. It means resituating or rather, it would seem, creating a strategy for people with high underlying clinical risk that extends well beyond clinical policy. As one person said: "There needs to be a strategic plan for all CEV as to preventative measures such as masking, hepa filters, better ventilation in buildings, access to anti virals, booster programme etc". It also fundamentally reframes the communications task.

4. Revising understanding of risk and inequalities

According to the revised Strategic framework "equality, human rights and inclusion remain at the heart of our ongoing response… We cannot let it become established as a disease of the poor, disadvantaged or clinically high risk".[6] Regrettably, that has not translated into action and impact. Meanwhile, it is vital that the spectrum of risks is understood. As one person said: "We are disabling the current as well as future generations. People need to be told about the real risks of living with biohazard virus."

Initially Covid, and now responses to it, have had and continue to have a major impact on a wide range of equality groups, fuelling numerous pre-existing inequalities, generating new dynamics and expressions of inequality, new societal faultlines and inequality groups. There has been a failure to grasp the multi-faceted nature of risk – as one person observed: "Don't just take into account medical risk. There are social situations that place people at

[5] See: https://healthandcare.scot/default.asp?page=story&story=3102; https://healthandcare.scot/default.asp?page=story&story=3018; twitter thread: https://twitter.com/SalWitcher/status/1496035148965552130

[6] See p20 https://www.gov.scot/publications/coronavirus-covid-19-scotlands-strategic-framework-update-february-2022/

risk.". Unmitigated risk plays out in all manner of inequalities. Misunderstanding of this runs right through the strategic framework, policy, communications and impact, like a stick of rock. There is much more to say on this, but broadly risks, need for action to mitigate, and scope for inequalities can be divided into three sections:

- Clinical: pre-existing conditions, frailty, genetic factors, extent of vaccine protection, access to antiviral protection, Long Covid (risk and clinical impact), by association
- Exposure: degree of virus concentration in air, proximity to others, numbers of people in a setting, frequency of people coming and going, risk status of others in the 'interaction chain', prevalence of mask wearing, type of mask
- Social barriers: attitudes, environment (Covid-safety), transport (Covid-safety), communications (as discussed throughout this evidence), if things are organised (to minimise risks), extra costs/ reduced access to earnings, access to justice.

The latter relates to the social model of disability, which says it is not necessarily an impairment that is responsible for disability but the creation of social barriers because society does not accommodate people with impairments. By analogy, if is not clinical risk that makes a person vulnerable but a) failure to contain exposure to the virus and b) the social barriers generated by, or generating, both.

When it comes to Covid, all 3 sets of risks have implications for equality groups well beyond disability. For example, there are implications for groups defined by age, gender, race, socio-economic status, due to such factors as workforce demographics, which groups disproportionately work in front-line, frequent exposure roles, unpaid carer roles, etc

One person asked: "What equality impact and harms analysis has Scot Gov done given how many we think are affected by the living with Covid approach?" Of course, if the nature of risk and subsequent inequalities is not fully understood, and therefore is not reflected in strategic approach and subsequent policy, carrying out a supposed Equality Impact Assessment is not going to tell you anything useful about impact and harms. Equality Impact Assessments, if carried out, are often poor. Where they do highlight equality implications more accurately, it can be impossible to discern how the assessment bears any relationship to action not/ taken[7]. Another remarked on how understandings of access and inequalities need to change to accommodate the impact of Covid and responses to it: "What can be done to influence/change the usual meaning of the word "accessible" in equalities terms (for workplaces, public spaces, events, & so on) to also mean "safe" (for everyone, but especially CV people & carers). Huge chasm now opening up along this fault line."

[7] See, for example p17: https://www.gov.scot/publications/resource-spending-review-equality-fairer-scotland-statement/documents/

Scottish Government has done good work on equality in the past. To argue there is little they can do would not be backed by evidence of past performance. Neither will the crisis in inequality be adequately addressed by a refreshed disability equality strategy to be published in 2023. For any government committed to equality, human rights and inclusion, the time to put that commitment into action is well overdue.

5. Misunderstanding who we are people

The relevance of understanding the groups at risk is vital for communications. This is how you segment target audiences, identify communication needs, appropriate methods, access issues and communications channels. A key starting point for communication strategies is 'customer insight', as in understanding the motivations, self—image, etc of the target audience in order to gauge how messaging will land. It is also vital for understanding diversity within groups.

The failure to understand the diversity of people within the 'CV'/ 'CEV' (clinically vulnerable/ clinically exceptionally vulnerable) groups has long been remarked upon. One respondent described it as "stereotyped (granny instead of young CEV)… & poor at communicating to the public who were/lives of CEV".

Another spelt out both the diversity and the scale: "Those of us who have chronic long-term conditions aren't a minor (tho marginalized) part of society. Adding together of those in this position probably runs into the millions. We aren't 'other'. It may be annoying to have to consider our needs but we are your daughters, mothers, neighbours, colleagues, service providers etc".

Communications that stereotype people at high clinical risk as elderly, already ill, economically inactive', vulnerable (with its associations of passive, needy and helpless) can have direct and damaging repercussions. General public health messaging, if it acknowledges the existence of people with high clinical risk at all, positions us as 'other'; as 'the vulnerable', whom others should remember to protect; as encumbrances on other people's rights and freedom, not as active equal citizens with equal rights and freedoms. Protections against infection are positioned as necessary just for us and cast as restrictions on other people's freedom: "Changing the language used (eg restrictions to protections) could help change public attitudes & perceptions around need for masks & ventilation so that they are more willing to help protect those at high risk.", said one.

All this has, unsurprisingly, bred resentment towards us: "people who are vulnerable to covid and remain at risk face a population which has been told everything is ok so is unwilling to protect us."; "We have an empathy crisis in the UK and part of that is because the many don't know what the few are going through." To draw attention to the perspectives of people at high clinical

risk, Long Covid and unpaid carers is to risk becoming a target for abuse[8]; accused of demanding lockdowns for all and that the majority should have their freedom restricted just to accommodate a minority. We are told that 'the disabled' should be grateful for any support at all given as they don't contribute economically. We are told it is just a cold and/ or we are cowards. Everyone's going to die sometime anyway and if we're scared we can hide behind the sofa. We were already anyway ill/ old before the pandemic, so what's changed? People wearing masks often report being made to feel the odd ones out, attracting questioning looks and even hostility. We are seeing new forms of hate crime emerge, online and in-person, driven by disinformation and misinformation

A further consequence is that the risks to anyone of long-term damage and disability from Long Covid are not adequately conveyed nor widely understood. There was much comment on this: "Reinforce message that anyone can develop Long Covid from Covid, however mild & it can be a multi system disorder. Long covid is SERIOUS, not short term & causes actual documented damage."; "The public should know that even mild cases of covid can lead to organ (brain, liver, heart) damage + that covid related thrombotic vasculitus is a serious illness, otherwise known as long covid"; "people need to understand the potential for life changing harm that comes with each infection, even for previously healthy people. I have been chronically disabled by Long Covid as a previously healthy and active 36yr old. There is no help for us. Tell them that."

6. Targeted communications

There is little targeted information and specific channels through which Scottish Government reaches specific groups. People at high clinical risk, therefore, rely on the same channels and receive the same messaging as everyone else. It is important to note, though, that messaging can land in very different, sometimes polar-opposite, ways, thereby fuelling the sense of being gaslit and underlining social exclusion. For example:

- I am confident most people will continue to wear masks..they should be mindful of protecting the vulnerable = We're not confident at all, and it only takes one non-mask-wearing infected person to infect us. Plus you're telling us we have no right to be protected from harm. Our safety depends in other people's good will.
- Everyone wants to get back to normal and have restrictions lifted = the lifting of 'restrictions', i.e. public health protections, is what stops people with high underlying clinical risk, unpaid carers, etc from getting back to normal.

[8] See, for example, comments on this article: https://www.thetimes.co.uk/article/covid-freedoms-keep-the-at-risk-trapped-in-homes-ckswbnzkf

- Show Covid Sense and get vaccinated = many people formerly on the HRL, unpaid carers and others would have been incredibly pleased to have had the opportunity for a Spring booster but were not eligible.

The Scottish Government closed the Highest Risk List on 31 May 2022 and redefined who it regarded as being still at highest clinical risk, based on the impact of vaccination on reducing risk and the development of new antiviral treatments. The last letter from the Chief Medical Officer, a vehicle that could still be a valuable communications channel, included a link[9] (inaccessible to some) to the evidence on which the decision had been based. This consisted of out-of-date, demonstrably less than robust, far from comprehensive and highly inaccessible research on the impact of vaccination, hospitalisation and death-rates. It is indisputable that early stage vaccination had a positive impact on those rates with regard to the variants prevalent at that time. Clearly, there were issues for people with immune suppression who could not produce antibodies. However, very importantly, there was no evidence of the duration of vaccine protection, of underlying exceptionally high clinical risk having been reduced long-term, of why waning vaccine protection was deemed adequate for new variants[10] particularly for people with that underlying level of risk. Consequently it is inexplicable why many formerly on the HRL were not eligible for additional boosters or antivirals despite these being given as the reason for discontinuing the HRL and deleting the data. It left many questions unanswered[11] including how it could possibly make good sense to discontinue a list of people with exceptionally high underlying clinical risk to this kind of virus and instead base that decision on the variabilities of vaccine protection.

The CMO announced that responsibility for people, other than the designated few who can't produce antibodies, was to be individualised - passed to local clinicians. He directed individuals to speak to their GP for advice, as the people who know their personal circumstances best. GPs were therefore positioned as the primary conduit for information. Unfortunately, they have not, though, provided GPs with the power to prescribe extra boosters or antivirals, regardless of their clinical judgement on the individuals ongoing level of clinical risk. Moreover, as my GP explained to me when I asked for his advice on HEPA air filters and types of mask "Not my thing. That's public health. We do clinical".

Information was provided about where to go for support with shopping, or if people are feeling anxious about adjusting back to normal and need a bit of support to build their confidence and rebuild social networks. In the face of wholly justifiable anxiety at the appalling situation confronting us, this landed very badly. Another key message promoted the 'Distance aware scheme'[12]- a

[9] See: https://www.gov.scot/publications/review-evidence-scottish-government-advice-people-scotlands-highest-risk-list/

[10] See, for example, "BA.4/5 is substantially (4.2-fold) more resistant and thus more likely to lead to vaccine breakthrough infections": https://www.biorxiv.org/content/10.1101/2022.05.26.493517v1; https://www.thelancet.com/journals/laninf/article/PIIS1473-3099(22)00365-6/fulltext?s=09

[11] See Twitter thread and responses: https://twitter.com/SalWitcher/status/1531948378682187783

[12] See twitter thread and comments on the Distance Aware Scheme: https://twitter.com/SalWitcher/status/1531216502891986944

small badge with a shield on it/ lanyard people can wear to signal (if anyone else can see it and knows what it means) that people are asked to keep socially distant. As was remarked, this positions us as the modern-day lepers. And it is all we have been left with to protect ourselves!

There was no recognition of the information people at highest clinical risk really need. For example, although decisions on eligibility for antivirals had been taken in January, healthcare professionals had been informed in February and the CMO had written to people on the HRL in March without mentioning it. There was a lot of comment on the need for Evusheld and queries on why it is not made available. A burning question now for people with high underlying (unprotected by waning vaccine protection, coupled with some possible new variant vaccine escape) clinical risk is who is and is not included in 'people at high clinical risk' eligible for the Autumn booster.

7. Accessibility of information

The diversity of people with high clinical risk signals that thought needs to be given to using multiple channels for both general and targeted communications. What is accessible to some is not for others. There has been some action on BSL and captioning, but none I have seen on Easy Read.

There were several comments, including by email, on accessibility challenges.

"The info about eligibility for antivirals was not that easy to find. The explanations about lack of eligibility for many at risk even harder and, when found, are unconvincing. The impression given, misleadingly, is that they are available to all at risk"

"The CMO letters had a section "if you have any questions" which contained the information that you should not send questions to or reply to any texts received. That was it. there was no offering for where you could ask questions instead. Given that some of those receiving the letters can't access the internet those letters and leaflets were all they had."

"the government website with the covid advice was unsearchable. you got every result of every document containing that word going back years. the section on covid got bigger and bigger with each guideline produced, but there was no way to narrow it down. just masses of results."

"I did manage to speak to my GP surgery a few times in 2020 and early 2021, I was constantly told (first in the recorded message before you even got through, then by receptionist or GP) that they could not answer questions on covid, on risk, on transmission, on vaccines, nothing, because they didn't know. it took a lot to get me and mum on the home vaccination list in early 2021."

"my rheumatology dept, that's not all that's wrong with me, but that's the only dept I have outside of GP, my other stuff is ignored by NHS, this will be

common for many - the juniors that did my follow up phonecalls refused to discuss covid, see above. My lovely nurse on the helpline tried, but got nowhere. She said try Public Health and my Board NHSGGC. the reply I eventually go from them was so simplistic I feel embarrassed for whoever wrote it."

"2. attempts to contact ScotGov directly. given we had no point of contact my initial attempt to get a question answered took 7 months to get a reply from CEU (central enquiries unit) which informed me of the FACTS campaign and said a decision had been taken to prioritise general public health messaging over individualised advice."

8. Overall verdict

There seemed much consensus along the lines that public health messaging is awful; pretty useless. There was also anger. One said "public health information was completely replaced by #disinformation." There was misinformation: "As well as telling everyone the wrong thing about vaccination, so people threw caution to the wind. This was criminally negligent." Another said communications were "often misleading (hand washing instead of airborne)". One later tweet bluntly expressed the anger many people feel: "Nobody wears a mask now, we have had numerous concerts in the past week yet no masks, no testing, no HEPA anywhere, I am livid…"

One summed up the problem with the messaging: "Public health messaging has been extremely poor. It feels like covid is being ignored & the protections eg masks, contact tracing, testing, self-isolation withdrawn. V little acknowledgment of long covid, ventilation, protection in schools, vaccination for under 12s, boosters etc".

Another (popular) response highlighted three key issues: "1. Mixed messages - it's "mild" but you should protect yourself 2. Too much focus on hand washing so many don't understand the transmission in the air and how that can be stopped 3. Polarisation of freedom vs lockdown. Having a range of protections like masks isn't lockdown". The latter point was echoed by others, e.g. "Public messaging seems to be death or recovery and lockdown or freedom."

For people at high clinical risk "Communication was very general and wasn't useful if you were particularly vulnerable. Even with the CEV group there is a vast difference in terms of risk. Developing more specific guidance is important." It was "poor at communicating to the public who were/lives of CEV. Vaccine booster/Evusheld communication hopeless." And, as we have seen, there was a lot of commentary on the silence and consequent misunderstandings of Long Covid.

Other comments concerned the situation for children: Children & teachers getting really sick in school, why isn't nothing being done?"; "if we want to protect our children we have to put them in awkward social positions like wearing a mask when no one else does."; "There are no antivirals for people

who already have long covid and get infected again. There are no boosters for us either. I work in a school and we are the highest group of Long Covid sufferers and there is zero protection. Abandoned". Others feel abandoned too: "Messaging has been absent for quite a while now & I feel as CEV person left on my own."

One also commented that "Science and protections have been abandoned". There has been a failure to position protections positively: "Protections that prioritise the vulnerable benefit everyone. Plenty of us weren't knowingly high risk before we got Covid; it can ruin the healthiest among us. EVERY reinfection increases risk of long-term harm. Fatigue isn't tiredness or apathy; it's debilitating." Another highlighted how language frames attitudes: "Changing the language used (eg restrictions to protections) could help change public attitudes & perceptions around need for masks & ventilation so that they are more willing to help protect those at high risk." It can change how people understand risk and attitudes towards people who still experience high risk: "There's been too much "after covid, living with covid" etc we know we are at risk some of us can't live with covid it will kill us. People who are vulnerable to covid and remain at risk face a population which has been told everything is ok so is unwilling to protect us."

Annex

Twitter thread:
https://twitter.com/SalWitcher/status/1536637814883897345

Calling people at high clinical risk, unpaid carers and people with Long Covid. On 23/6 I'm giving evidence to the Covid-19 Recovery Committee's inquiry into the communication of public health information. What would you say to them? [grateful for retweets!]

The session is on whether public health information about COVID-19 is accessible to and meets the needs of specific audiences going forward, including people in the shielding category and communities where there has been below average uptake in vaccination to date.

In a week when we're told a new wave is coming/ already here, herd immunity is probably impossible, long covid is a problem, boosters should be offered to all adults but hey! don't panic, no need for restrictions (i.e. protections) what are we supposed to do?

Clear warnings alongside 'nothing to see here, as you were'. Talk about mixed messages! Unfortunately lives depend on getting this right. Don't know about you but there's a lot I want to know including why @scotgov seems to be saying nothing helpful & is just sitting on its hands.

Biographical note

Dr Sally Witcher OBE currently works as a freelance consultant. She has a track record of over 30 years working in the equalities, poverty and social inclusion fields, in a variety of senior roles, including CEO of Inclusion Scotland and the Child Poverty Action Group UK, and as a senior civil servant in the Office for Disability Issues, DWP - a cross-governmental unit charged with rolling out the then government's strategy on improving the life-chances of disabled people. In the latter role she had responsibility for the ODI's communications team. She has considerable academic experience, including as a member of the advisory committee to the LSE's Centre for Analysis of Social Exclusion and a Phd on diversity and inclusion, and has held various public appointments including, latterly, Chair of the Scottish Commission on Social Security.

Sally has been a disabled person since childhood. She has complex co-morbidities, including conditions related to immune system malfunction, lung damage/ multiple respiratory issues, circulatory issues and high blood pressure – all well-managed and enabling her to work 60plus hour weeks in senior roles. She was placed on the Shielding List (then Highest Risk List) by her GP, who still describes her as being 'predisposed to a poor outcome' should she be infected with Covid. She is, however, not considered by Government to be at high clinical risk. Her booster was over 8 months ago and she is ineligible for additional boosters and antiviral treatments. She has consequently been shielding throughout and has no prospect of leaving her house safely in the foreseeable future. She is not happy about it!