


How Can We Dismantle Health Inequity Together?

National Voices' conference to realise the power of the voluntary sector

March 2021



Making what matters to people matter in health and care

A background image showing a grid of approximately 15 Zoom meeting participants, overlaid with a semi-transparent purple filter. The text 'HOW CAN WE DISMANTLE HEALTH INEQUITY TOGETHER?' is centered over this grid in white, bold, uppercase letters.

HOW CAN WE DISMANTLE HEALTH INEQUITY TOGETHER?

National Voices' conference How Can We Dismantle Health Inequity Together? ran over four Tuesdays in March 2021, with each day focused on a different theme. The conference set out to explore the VCSE health and care sector's role in tackling health inequality, and was supported by the Health Foundation and PPL.

Over the conference, we covered the VCSE sector's role in responding to the unequal impact of COVID-19, explored opportunities for cross-sector working and identified influencing priorities, while discussing how to tell stories of health inequality that will be better heard by decision makers.

We emerged from the conference with a greater understanding of health inequality, and with a greater commitment from charity colleagues, funders and partners to address this social dimension of health through their work.

Attendees

We welcomed attendees from VCSE organisations, the NHS, academia, patient groups, government and beyond. They were given a range of ways to engage with sessions, from passing comments in the chat, contributing questions via Zoom functionality, engaging with interactive activities and via the Mentimeter tool, which generated word clouds or 'post it notes' to capture the thoughts and feelings of attendees and these received high levels of engagement.

We live-tweeted during the conference, gaining high levels of engagement and interest. If anyone wanted to re-visit the conference or if they were unable to attend, the sessions were uploaded to YouTube within 24 hours and the 10 videos collectively have received over 1,000 views.

We ensured accessibility by asking questions when people registered for the event and sent slides ahead of time in a standard or plain text format to people who needed them. Additionally, we used a palantypist ensuring closed captions were more reliable than auto-captioning. For all attendees, we circulated the Mentimeter graphics along with the Powerpoint slides following each day of the conference, and re-shared the link and agenda ahead of each session.

Conference Day 1 - Poverty

The first session of our online conference saw Sir Michael Marmot, the Health Foundation's Jo Bibby and campaigner Sandra Jayacodi join National Voices Chair Helen Buckingham and CEO Charlotte Augst for a discussion on the big themes around poverty and health inequality.

Sandra provided insight through her own experiences, and Jo looked at the socio-political context and the way public opinion could shape policy shifts. Sir Michael decried the resurrection of the idea of the "deserving and the undeserving poor" and the culture that blames people experiencing poverty for their own health woes.

In our first member-led session, representatives from National Survivor User network, the Centre for Mental Health and the African Health Policy Network turned the focus onto poverty and mental health. The final session was led by the Patient Experience Library, Groundswell and Turning Point and looked at partnerships and the power of peer-led approaches.

Conference Day 2 - Race

Day two of our conference focused on issues around racial injustice in healthcare. Diversity and inclusion expert Sanisha Wynter gave a powerful account of her own experiences with mental health services in the opening session. She was joined by the Runnymede Trust's Halima Begum, who focused on issues of system design, and Dr Habib Naqvi, who spoke about the work of the NHS Race and Health Observatory. The member-led sessions in the afternoon saw a Resuscitation Council UK-organised workshop explore partnership working, and later on Youth Access and Birthrights gave detailed insights into the work on the ground they are doing to tackle issues of racial injustice with their teams, partners and communities.

Conference Day 3 - Digital

On the third day of our conference we focused on 'Partnering up to combat digital exclusion'. In the first session we heard from Hameed Khan, who spoke about his experience of using health services and finding himself locked out by digital exclusion. Emma Stone of Good Things Foundation talked about their work trying to improve digital access for people, and James Watson-O'Neill detailed his organisation's experience as a Deaf health charity trying to help Deaf people get support and treatment in the pandemic. In the member-led portion of the conference, the Patient Information Forum ran a session with Connect Notts and Belong Notts and they spoke of their work together, reaching through partnering deep into communities. Reaching People and MoneyWise Plus talked about their work in Leicester and once again stressed the importance of collaboration. In the final session of the day Compassion in Dying, Macmillan Cancer Support and Future Care Capital joined up to look at 'the human in digital storytelling' and explored the good and bad of trying to engage people digitally, the power of first-person storytelling, and the way fiction writing can open up dialogue.

Conference Day 4 - The Future

The final session of our conference saw a packed line-up discuss the proposition 'How we can take action together'. Expert by experience Marsha McAdam gave an insight into her experiences of health and care with multiple conditions, and her overview of the conference. National Voices CEO Charlotte Augst reflected on the learnings from the conference. Daisy Sands from the Joseph Rowntree Foundation talked about poverty and ill health, and Professor Dr Durka Dougall from the King's Fund discussed what is necessary for good partnership working between the statutory and voluntary sectors.

Dr Bola Owolabi, Health Inequalities director at NHSE/I and a GP, followed on looking at how people are impacted by inequalities in their wider lives and how this translates into their clinical needs, with a focus on the vital work of the voluntary sector. National Voices Chair Helen Buckingham brought the conference to an end, again highlighting the commitment to bring people and organisations together to form a network to progress the work on tackling health inequity.

A large background image showing a grid of many small video conference windows, each containing a different person's face, overlaid with a semi-transparent purple filter. The text 'NATIONAL VOICES' CONFERENCE TO REALISE THE POWER OF THE VOLUNTARY SECTOR' is centered over this grid in white, bold, sans-serif font.

**NATIONAL VOICES'
CONFERENCE TO
REALISE THE POWER
OF THE VOLUNTARY
SECTOR**

HOW CAN WE DISMANTLE HEALTH INEQUITY TOGETHER?

DAY 1 - POVERTY



The first day of the conference focused on the intersection of poverty and health inequality. The introductory session featured Sandra Jayacodi, a health advocate, Sir Michael Marmot, Director of the Institute of Health Inequality, National Voices CEO Charlotte Augst and Jo Bibby from the Health Foundation. The second session was a National Voices member-led session organised by the Centre for Mental Health and National Survivors User Network. The final member-run session of the day was co-produced by Groundswell and Turning Point.



Sandra Jayacodi's conference experience

"I spoke about poverty and health inequities following my own experiences of failing to access care or manage my health due to stigma, culture, poverty and lack of confidence. Later talk triggered important questions, such as how the voluntary sector, local communities and the public can play a vital role either on their own or working in partnership to combat health inequities. The afternoon workshops on 'Poverty and Mental Health: exploring the problem' and 'Using partnerships and peer-led approaches to tackle health inequities' were thought-provoking and insightful. Maureen spoke bravely about normalising mental health, which I welcome. I have provided peer support services as a befriender and the benefits are overwhelming. One thing that I will take home from this conference as an individual and member of the public is the importance of empowering people in my community to understand that our own circumstances impact our health."

360

Attendees for session 1, day 1

FEEDBACK

"Experts by experience kicking off every day's sessions - brilliant!"

"I've learned a lot. The quality of the speakers was fantastic and they all had slightly different perspectives"

"It was fascinating to hear from all kinds of charities and how they've tackled inequalities"

"Michael Marmot is straight-talking and clear. The lack of progress and decline in health equality is frightening"

People watched the morning session later on YouTube

299

SESSION ONE

Intro session - Poverty

- Sandra Jayacodi talked about her experiences of being ill, losing income, and then developing mental health issues
- Michael Marmot said the UK needs a cultural shift where poverty is tackled as a root cause of health issues
- Jo Bibby argued public sentiment was key to creating positive change
- The Mentimeter exercise showed attendees felt Action and Collaboration were key
- Helen Buckingham said ICS reform offers the opportunity to get inequality and inequity into the conversation

SESSION TWO

Poverty and mental health

- Amy Wells from NSUN outlined how people in poverty become ill due to stress in their lives
- Andy Bell asked what a system would look like that was designed to create equality for people
- Maureen Ndawana talked about her work with immigrants and how pressures build over time
- Questions covered the ways issues intersect; what disempowers people; and what VCSEs can do
- Attendees identified Housing, Education, Funding and Employment as areas where change could be made

SESSION 3

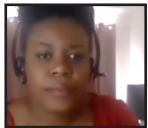
Peer-led approaches

- Turning Point and Groundswell described how they collaborated on projects that were peer-led
- They described how they shared activities and worked to compromise on different priorities
- The importance of local versus national was discussed, as was 'the power of the peer' in engaging and helping clients.

Impressions for tweeted quote from Sir Michael Marmot

14,845

This second day of the conference focused on the ways the voluntary sector can work together to combat racial injustice. The opening session featured expert by experience Sanisha Wynter speak about her experiences and the broader picture for people of colour accessing health services, alongside representatives from the NHS Race and Health Observatory and the Runnymede Trust. Later sessions looked at issues around resuscitation and working with communities, and also at how race effects maternity and youth services.



Sanisha Wynter’s conference experience

“This topic (racial injustice) matters to me as the disparity in statistics are stark and impact the engagement and feed into the culture of distrust minoritised communities may feel when accessing health services. As the first speaker of the introductory session and the expert by experience, I thought it was pivotal to set the day’s tone by sharing how racial injustice and health inequity have a circular relationship and cannot be addressed in isolation. I wanted to share my personal experiences and barriers when accessing mental health services, and the impact racial bias can have on treatment and recovery. I feel the obstacles are a lack of trust, stigmas, stereotypes, and health services not being tailored to Black people. I also reflected on how the narrative ‘Strong Black Woman’ can be harmful and dismissive when asking for help. I mainly wanted to encourage action and collaboration by the VSCE sector to acknowledge the statistics we are aware of and share tangible learning by sharing the best practice.”

170

Mentimeter responses in one session

FEEDBACK

“One of the most enjoyable but also most emotional conferences I have attended during lockdown”

“Overall I thought it worked extremely well and was very smooth”

“It is hard to hear of the inequity in health and care, and sometimes to feel so inadequate”

Most shared conference tweet was announcing the day’s agenda

1

SESSION ONE

Intro session - Racial injustice

- The links between health inequity and race have been made clear by COVID-19, says Dr Rebecca Steinfeld
- Sanisha Wynter says racial biases mean people of colour are treated differently and don’t trust services
- Habib Naqvi outlines the aims of the Race and Health Observatory
- Helima Begum highlights the deaths of 60 BME NHS staff among the first 100 to die from COVID
- Panelists suggest orgs collaborate at local and national level to address racial injustice in health and to also focus on social determinants

SESSION TWO

Resuscitation and community

- Resuscitation Council UK say being saved by resuscitation can depend on ethnicity and socio-economic status
- Gurch Randhawa says tackling inequalities requires partnerships
- Andrea Ttofa outlines the importance of engaging locally
- A project is covered that teaches people about CPR in mosques
- Questions focus on how funding needs to reach local communities, the importance of trusted groups, and the need for more diversity
- Mentimeter: a need for more Funding, Listening and Understanding

SESSION 3

Working with inclusion

- Birthrights and Youth Access detailed transformative projects with race at their heart
- They described how difficult conversations and activities can be made safe, effective and positive
- Their approach to the session was: It starts with you; Be led by experts; Create safer and braver spaces; Commit to move, and move.

Tweets sent by the conference team on day 2

75

HOW CAN WE DISMANTLE HEALTH INEQUITY TOGETHER?

DAY 2 - RACE



Mentimeter interactive results - Day 2 continued ...

How do you commit to move [on racial injustice]?

Feedback to my BMA Patient Liaison Group colleagues as a start	work in collaboration with other to make changes happen.	Go back to my senior management team and push harder for change within our organisation
Talk about what I have learnt today in my next team meeting and ask what we can do as an organisation to address health inequality	We will review recruitment, our Board and how we partner up with others. We will platform more diverse voices. And we will focus our work on inclusion and ask questions about inequality in everything we do.	Increase my awareness of the outworking of discrimination.
Putting a plan and actions together in partnership with patients and carers	Meeting like minded people and being inspired and made aware of the discrimination that others are facing and what others are doing to tackle this	Take this idea of BRAVE space to discussions I take part in.
Bring this learning back into my organisation and encourage people to respond to this inquiry	Make a stand against discrimination in all its forms.	reviewing E & D policy and implementing action plan for action to change
Contributing bravely rather than being a passive bystander	Start planning, building partnerships, forming focus groups	challenge the board selection
Start with small steps and hope this mobilises an army	Supporting the anti-racism work in my organisation and sharing some of the key messages from today	I will continue with my Human Rights work, learning from and leading peers to be brave and active in challenging discrimination.
Investing in staff and volunteer learning and training	mobilising the voluntary sector through infrastructure orgs - larger voice - collaborate with commissioners build evidence base inc qualitative is ok.	To ask the VCSE organization to look in on itself and be honest about what it sees
Working on board and staff recruitment	Recognise the impact of generational trauma on families especially those from diverse ethnicities/cultures/backgrounds.	I want to hear young people's views
I will raise the issues raised in this conference and talk about what we can do to increase our workforce diversity - i will work personally to increase our volunteer diversity and i will work not to be the silent passive person in future. Heather	Personally, not to be passive, but to identify and acknowledge racism	Inform the majority about how people are suffering in this country and see if they care and if not why not? Improve the message accordingly.
Continue to challenge inequalities. Work with move makers and bring more awareness executives.	Help gather evidence of people's experiences so we can begin to find out the extent of the problem. Help put together a strategy of how we're going to take our EDI work forward.	Find allies, co-leaders, pay people of experience
Liaising more with underrepresented communities	Start conversations within my organisation and look for training and education for our staff. Also engage with communities and understand needs	Facilitate access to quality health and social care from pre-conception to grave.
Working on culture change and making this central to our values	Talk with my local CCG colleagues to see what they are doing in relation to Maternity Care.	I will ensure I don't accept stereotypes blindly and listen to the person

HOW CAN WE DISMANTLE HEALTH INEQUITY TOGETHER?

DAY 3 - DIGITAL



Day 3 saw the focus turn to technology in healthcare and the increasingly damaging phenomenon of digital exclusion. The Good Things Foundation gave an overview of the barriers people face and SignHealth and Hameed Khan outlined their experiences of battling technological issues. Groups from Nottingham and Leicester explained what they were doing on the ground working in communities, and the final session explored the power of storytelling and identifying the 'human within digital'.



Hameed Khan's conference experience

"My session was about the importance of understanding digital exclusion and inclusion and the fine line between the two. I had open heart surgery in 2019 and during the pandemic I was asked by my heart consultant to have a video conference call which I was able to participate in - on the other hand my mom, who doesn't speak English and has no technology skills, faced multiple barriers during the pandemic. We spoke about how do we challenge some of these digital exclusion barriers and ensure people gain skills to become digitally competent. We discussed other factors such as data poverty and devices. One (afternoon session) was about looking at the human in the digital and the other was about looking at how organizations work in terms of supporting and enabling and offering services online; and one of the things really importantly that was discussed was that even though there is digital it is very important when providing services to have the compassion, the care."

964

Views for tweeted video by NV staff member promoting day 3

FEEDBACK

"It was fabulous from start to finish"

"The digital inequity talks spurred me on to take up the problems with my GP surgery with Healthwatch and the local carers hub to make sure no else without a mobile phone would slip through the cracks"

"Local solutions, practical ideas, new ways of looking at things - and the candour of your speakers!"

Attendees for morning session

236

SESSION ONE

Intro session - Digital exclusion

- Jess Brayne highlights the National Voices work The Dr Will Zoom You Now
- Emma Stone says 7m people don't have the internet and argues we must close gaps
- Hameed Khan says the first time he felt illiterate was when health services moved online in lockdown
- SignHealth explain the BSL Access project to help deaf people in COVID
- Attendees vote Lobbying, Amplifying Voices, Raised Awareness as key
- Questions focus on differences between local areas/affluence and how the system should respect people

SESSION TWO

Improving digital literacy

- Patient Information Forum introduces key facts around digital literacy
- The session explores how the NHS in Nottingham works with community groups, including a digital support line
- Reaching People Leicester outlines work to bring people together and about advice centres in foodbanks
- Moneywise Plus talks about holistic approaches to health, work, digital
- One-to-one assistance and not making assumptions is important
- NHS outlines importance of word of mouth, GP, voluntary sector and community groups working together

SESSION 3

Power of story

- Compassion in Dying have found successes and challenges in using digital to reach people
- Macmillan says they have found ways of getting people to tell stories and empower themselves
- Future Care Capital explain how they have used fiction to explore technological advances in healthcare.

Engagements for Patient Information Forum conference tweet

351

HOW CAN WE DISMANTLE HEALTH INEQUITY TOGETHER?

DAY 4 - THE FUTURE



The last day saw a plenary session with a packed line-up hoping to look to the future and establish what the VCSE sector could and should be doing to tackle and dismantle health inequality in all its forms. The conference welcomed Dr Bola Owolabi, Director of Health Inequalities at NHS England and Improvement, mental health influencer and advocate Marsha McAdam, the King's Fund's Professor Dr Durka Dougall, Daisy Sands from Joseph Rowntree Foundation, National Voices CEO Dr Charlotte Augst and National Voices Chair Helen Buckingham.



Marsha McAdam's conference experience

"I was asked to listen in to days 1-3 of the conference. At the time the language was hard to understand. One thing I'd like you to think about is that if we need to change things, everyone needs to understand them. This was something that Sandra Jayacodi spoke about on the first day of the conference. On Day 2 of the conference, on the day discussing race inequality, Sanisha spoke about what it's like to be a black, bisexual woman with BPD and mentioned a worrying statistic where black women were five times more likely to die as a result of pregnancy. A few years ago, I facilitated some workshops for the Centre for Mental Health, for their commission for inequality, and the intelligence gathered really helped them, and made me reflect on what I can do as a person to stand alongside people. This conference has been amazing and the messaging throughout has been: 'Enough's enough, we need to do something'. Now we need to move to that next stage."

200

Attendees for final session

FEEDBACK

"The whole conference has been brilliant and provocative"

"How it was split over four days and with short gaps between sessions - it provided processing and reflection time, so it wasn't information overload"

"Enjoyed the can-do nature of the final session and leaving it hopeful that there is energy and commitment to make a difference together"

Survey respondents who said the quality and diversity of the speakers was the best thing about the conference

50%

FINAL SESSION

What we can do together

- Marsha McAdam attended the entire conference and gave her views of the breadth of experiences and voices she had heard
- Marsha also detailed her experiences of health inequality and her feeling that the one-size-fits-all approach is very damaging
- Charlotte Augst said Marsha's words reminded us people are living at the very sharp end of inequality
- She looked back over the conference day-by-day and reflected that the system is failing people in different communities

- Charlotte committed National Voices to creating an alliance that focuses on inequality and fights for fairer health
- Daisy Sands said language and public opinion are vital in tackling inequality through poverty
- She explored the intersection of poverty and ill health
- Durka Dougall discussed the importance of the statutory and voluntary sectors working together
- She said VCSE orgs bring authenticity and place-based advantage
- Bola Olowabi identified how the NHS must work more closely with the voluntary sector, sharing resources
- She said the role of the VCSE sector

is around advocacy, intervention, insight, prevention and connection

- Discussion focused on how the health sector needed to align behind a shared narrative, and how to land arguments with decision makers
- Poll: attendees made pledges around Language, Collaboration, Influencing tactics and Self-assessment
- Helen Buckingham closed the conference highlighting the commitment to bring people together in a network to create real change in tackling health inequality.

Impressions generated by conference tweets

563k

HOW CAN WE DISMANTLE HEALTH INEQUITY TOGETHER?

DAY 4 - THE FUTURE



Mentimeter interactive results - Day 4

What should a fairer health alliance or network prioritise?



What do you pledge to do to help tackle health inequality?

Work (as a researcher) with Third Sector orgs in rural Highlands of Scotland to advance participatory research/co-production and develop a digital resource for group mutual aid for mental health recovery inc multi-morbidity.

Consider the needs of the most deprived communities when holding system leaders to account and considering changes in service provision.

Personally, and with my colleagues, to prioritize the spirit of friendship and, through seeking empathy, to hope to become more reflective and compassionate

challenge the decision makers. Oblige them to explain and justify. Patient reps can do that really effectively. Don't allow developments to widen inequality

Join anti stigma campaign re borderline personality disorder Learn more about JRF Be much more reflective and take deliberate steps to notice almost casual inequities it is too easy to accept as just the ways things are Use words better

To help challenge the health inequalities disabled parent of disabled children faced, due there disabilities being hidden and adress the late diagnoses BME group faced ?

Set up working group with staff in Moorland Community Care Group to address digital inclusion.

Continue to champion the voices of local people, and bring their experience to the centre of decision making conversations.

Our enthusiam! Wanting to make a difference for those impacted by cancer, we want to feed into the wider discussions and debates and share our clients experiences.

Continue to work on transparency and duty of candour in health so that all can be as informed as possible in decision making

Work with local VCSE organisations to learn about peoples lived experiences / barriers to accessing services and support so can consider how to co-design improved services

More engagement with south Asian health patients, carers and communities

Co-producing a common narrative and ambition with all partners across the North East and Yorkshire holding us all to commit to moving this agenda forward.

I would love for JRF to support (framing, strategy, influencing) with any sector wide campaign to address the link between poverty & health inequalities! I can't promise this myself but can take this to the org if there is interest in our support

Working with cancer patients and staff to understand digital exclusion - and to co-produce and pilot potential solutions.

help support those who live day to day with difficult circumstances, especially using language they use.

Keep raising it on the health agenda and encourage inclusion of patient voices

My job role is about this and I will ensure to examine all my efforts through this lens but most importantly I need my wider organisation to understand and examine the whole organisation way of working

HOW CAN WE DISMANTLE HEALTH INEQUITY TOGETHER? SUMMARY by DR REBECCA STEINFELD



Looking back, I am immensely proud of what we achieved. Despite the challenges of the last year, and our own personal and organisational fatigue, we managed to organise and host our first ever online conference.

We ensured people with lived experience of health inequalities were front and centre. We addressed urgent issues with openness, and without pulling our punches. By shining a light on three specific areas – poverty, racial inequality and digital exclusion – we were able to explore the breadth and depth of the problems that need to be solved. We were joined by brave and experienced leaders from the voluntary and public sectors. We worked with members to co-host workshops and ensured all of the sessions were accessible and offered numerous ways to interact. All of this took an immense amount of work, and I am thankful to everyone at the National Voices team and at our delivery partners PPL for going above and beyond to get this conference over the line.

On the one hand, I feel inspired by what I heard during each day of the conference - the openness of people with lived experience about their physical and mental ill-health, and the barriers they've confronted and overcome; the indefatigable work of fellow VCSE organisations to combat these issues; and the commitment and determination of system partners working from within the NHS to narrow gaps in healthcare access, experiences and outcomes.

At the same time, like others I'm sure, I feel somewhat intimidated by the enormity of the task at hand – the complex, multi-layered drivers of health inequity (income, housing, education, and so on), as well as the healthcare inequalities that need fixing. I'm keenly aware of the work that others have done before us over many years, and that despite their best will and efforts, the problems persist. We do not want to find ourselves here again in 10 years' time.

But I am hopeful though that our conference, alongside growing public awareness of the causes and consequences of health inequalities laid bare by COVID-19, will help us make progress. We can achieve change if we move forward together, reframing the issues and arguments; and if we work with people with lived experience who have the moral authority and determination to drive forward change. We have evidence and insight. And this last year has given the case for

tackling health inequity renewed urgency and energy.

We are working hard to build on that momentum. We have been discussing next steps - developing a coalition or a campaign are possible options. We thank those who have already expressed an interest in taking this work forward with us so that we can translate all of this energy into meaningful changes for people.

Dr Rebecca Steinfeld, Head of Policy, National Voices

WORDCLOUD: WHAT WAS THE BEST THING ABOUT THE CONFERENCE?



NEXT STEPS

We are currently undertaking a consultation process with conference attendees, National Voices members and other interested groups, and discussing with our staff team and Board of Trustees how to proceed in creating a vehicle for facilitating positive meaningful change on the issue of health inequity. As previously mentioned, we are looking at some sort of network that focuses on fairer health.

We recognise the urgency, but we also recognise the need to get things right from the outset after seeing so many false starts. If you would like to get more information on these plans or talk to a member of the team, please contact info@nationalvoices.org.uk.