Multiverse Lab: What We Heard

About Multiverse Lab

Since its launch in Autumn 2020, *Multiverse Lab* has reached 3,145 people across the North East and Cumbria. This innovative public engagement project asks people, **"What is the health or social care breakthrough you hope to see in your lifetime?"** It was developed with the aim of making communities' voices heard, including those under-represented in public engagement, to shape the future of health and social care research. It collected people's responses to create a 'lab of many voices'.

What We Did

Multiverse Lab reached 1,245 of the 3,145 people engaged through a touring pop-up installation. It visited high streets, community centres and festivals to reach diverse communities across the region. The installation featured bespoke recording software so people could add their voices. This technology combined with 2 hosts. The hosts encouraged passers-by to take part. They often found people didn't think they had anything to say. However, when they got chatting, many people realised they had experiences and insights that were relevant and needed to be heard.

Multiverse Lab also engaged 1,900 digital audiences. This engagement was born out of necessity as the lockdowns of 2020-21 made physical touring impossible. The team built an interactive website which was promoted via social media and via direct mail to community groups across the North East and Cumbria. What the team quickly realised was delivering a programme of Zoom Socials created 'moments of action' and reasons for people to come together to explore the website and add their voices. These Zoom Socials were a mixture of targeted sessions for particular community groups, and open public sessions.

Screenshot of Multiverse Lab website; Photo of Multiverse Lab on its community tour

We ensured our hosts reflected the diversity of the communities we wanted to reach. This included offering BSL and Urdu speaking hosts as part of the digital engagement. This content was also available via QR codes for the physical tour, offering better accessibiity. Our hosts were aged between 20-58 and came from different ethnic backgrounds. We were also joined by volunteers from VOICE and ARC to host the installation on tour.

Through these 2 strands of activity *Multiverse Lab* captured 500 voices. Below in this summary, we share what we heard and people's priorities for health and social care research.

What We Heard

The vast majority of people who added their voices to *Multiverse Lab* spoke personally. They talked about issues that affect them and their loved ones. They talked direct experiences and impacts on carers. They talked about 92 different issues, from common experiences to rare conditions.

Top Ten Most Talked About Issues

1) Cancer: 16% of responses [78 responses]

People talked about wanting to find a cure. This was often people's first response. Many people also talked about wanting research into earlier interventions and better tools to diagnose cancers. People also talked about wanting to find less aggressive treatments.

- *"So, I would have said bowel cancer. Very very concerning. I've lost 3 family members. My mother had it. It's not found fast enough. We need to talk more about bowel cancer and make it very clear at school and all through adult like."*
- *"Pancreatic cancer. More research into the markers because it's often too late. In the case of his granddad he had 3 weeks and then he was dead."*
- *"I don't think cancer is ever going to go away. But it's the improvement of the medications… Currently the treatment's quite brutal… Sometimes it's a difficult decision of whether to have treatments or not..."*

- *"I am 65 years old today and I have been suffering from prostate cancer. I didn't find the treatment very easy. I didn't think that they picked up on the prostate cancer very easily in the hospitals I attended."*

2) Mental Health: 14% of responses [70 responses]

Mental Health was the most-talked about issue by young people. People's responses focussed on the lack of support available and the need for better interventions. Concerns were voiced around mental health support for children and young people and the impact of the pandemic. Mental health was sometimes discussed in relation to addiction, stress, poverty and isolation.

- *I think mental health is you know… the pandemic has shown increasingly how important that is for everybody to look after… Young people as so much more switched on and able to talk about that. Hopefully that will be something that we can spread across all ages and particularly in the North East, where male suicide is, I think, the highest in the country."*
- *"I would like there to be more research into making it easier for people to get through every day with mental health and anxiety. Because I really suffer from it… I try my hardest. I go out everywhere, with my girlfriend. But I still have low days not matter how hard I try. I know mental health, especially with men, is really bad. And suicide rates with men are really bad."*
- *"Mental health. The biggest thing for us. Like she said, they would have still had their mam. We can only do so much."*
- *"I'm a mental health nurse and I've worked in A&E, liaison, I've worked street triage, ambulance service, police, prisons and everything screams to me we're underfunded. It's embarrassing for me. It doesn't make me feel very proud. I speak to people on lengthy waiting lists and they deteriorate in that time."*

3) Dementia: 11% of responses [54 responses]

Overwhelmingly people talked about the impact on families and carers. They called for research into how to slow, or even stop, the impact of dementia. People talked about our ageing population and calls for research into better ways to support those affected by the condition.

- "*My grandmother had Alzheimer's, my sister has got Alzheimer's, my brother's got some kind of dementia and my mother had multi-infarct dementia. I would like to see a breakthrough in dementia research because it takes people away while they're alive."*
- "*So, [my husband] suffers with dementia and he's had it since he was 60. But all we're doing is everything in retrospect. Instead of identifying dementia before it's started… We need to be identifying dementia in our 30s and 40s and knowing the propensity… then finding out what we can do to stop it. Getting medicine that can stop dementia rather than keeping it on an even keel."*
- *"I would like to see Alzheimer's disease cured within my lifetime. Just because of the destruction it causes families and the upset."*

4) Equality: 8% of responses [39 responses]

8% of people talked about equality. [39 responses]. Issues raised included racism and calls to improve the inequality in health outcomes for black and ethnically diverse people. People also talked about socio-economic inequality and issues around rural access to health and social care.

- *"One of the challenges of living in a rural area as we do in North Northumberland is access to healthcare and social care and the impact of isolation with living in a rural community."*

- *"I would like to see a socio-health breakthrough in the way that we as society look at disability and access. People want access, this should not feel like a burden but instead at the start of any process."*
- *"Access isn't there for enough people. So it doesn't matter how brilliant our research is. If the money is not there to disseminate it to a wide section of the population."*
- *"I would like to see a social change between medical practitioners and patients of colour. A lot of patients with colour either get dismissed or there is still archaic notions of … black people having a higher pain tolerance, which is totally untrue. I'd like to never have to hear of my mum or a friend having to go to the doctors and have to up what their symptoms are just to get considered. I'd like to see the fatality rate of black women in childbirth go down."*

5) Personalised Treatment and Care: 5% of responses [26 responses]

This ranged from people talking about community-based care, digital vs face-to-face contact (mostly but not exclusively preferring face-to-face) and social prescribing. Themes were building trust and holistic and individual approaches to health and social care.

- *"I want to see more holistic and personalised healthcare being the norm, so that people living with more than one illness or condition don't have to choose to treat one thing at a time and the doctors look at the whole person and their lives and also consider happiness and wellbeing rather than just 'health'"*
- *"Electronic Patient Record which include self-care and input from patients themselves."*
- *"I would like to see more research into personally targeted medication, not only, and especially not only in the rich countries of the world, but between rich and poor between the sexes between the ethnicities and so on and so forth, much more research onto personally targeted medication."*

6) Healthy Ageing: 4% of responses [21 responses]

The uniting theme of many responses was research into improving the quality of life for older people. This included responses about research into improving mobility, mental health, housing and social care. Responses often related to concerns about other health issues, including arthritis, dementia, incontinence and diabetes.

- *"People seem to think if you're older or disabled you have to live in a shoebox… If everything was just a little bit easier. Design was better. I can touch both walls of my kitchen. The bathroom I can do the same. In lockdown I was trying to do a dance class in my corridor. I had to get my chair in. If I wanted to use both arms I had to go sideways."*
- *"I'm very concerned about arthritis. My dad has suffered with it from the age of 35, practically in a wheelchair now. There must be something that can be done. And the final one is dementia. It absolutely terrifies me. That thought of not being able to remember your life… I think it's those completely debilitating diseases… when we're talking about ageing well.*
- *"Health repercussions of older age and worrying about health… Research into the impact of retirement and the impact it has on wellbeing, psychologically and physically. Programmes that encourage recently retired people to stay active."*

7) Social Care: 4% of responses [21 responses]

Many responses expressed frustration at the impact of under-funding for social care. People talked about issues relating to social care staff, costs and housing. Most people focussed on either social care in relation to older people or children and young people.

- *"There's something for me about our youngest and our oldest residents who need support or care in some way. [They] are often cared for by the people on the lowest salaries with the lowest qualifications. They're not really seen as being as important as those roles should be. Better join up between hospitals and social care. A huge issue about people's worries about their ability to pay for care."*
- *"Funding always exists in single streams, so mental health services or LD services, drug and alcohol. But people don't exist like that. People sit across the spectrum. What we tend to find is we'll get a lot of people into our homeless services that have been turned away from mental health because they've got drug and alcohol, or because they're also homeless. But they have a very severe mental health need. It's just about looking at people as a whole."*
- *"I work in social care and the service that I cover covers children to adults, so I do birth to death. Social care in general is underfunded... But the biggest area that's underfunded in mental health, particularly for people in acute crisis."*

8) Women's Health: 4% of responses [19 responses]

All responses came from women. Issues included endometriosis, gynaecology, menstrual cycle, menopause, miscarriage and antenatal care. It included frustration at the years it takes to get a diagnosis of endometriosis. Many talked about women's health issues like menopause or painful periods being written off as 'normal' when they deserved better understanding, investigation and treatment.

- *Endometriosis... So many lasses I know have been to the doctors in agony and it's just shoved off as acceptable pain. So, when you're talking about chronic pain. Stuff that's seen as just women's issues. Underfunded. That's just historically like that."*
- *"One thing that is very close to my heart is miscarriage… I don't think that that is something that we talk about enough. The statistics are something like… they're shockingly high that women's first pregnancy ends in miscarriage and when friends or family go through that I find there's little or no support and it's a taboo word. And I'd like that to change."*
- *"Menopause in women. It's very under covered and it's a big issue for a lot of women."*
- *"I was thinking about America and how women have gynaecologists. I was then thinking why don't women in the UK have some sort of regular health care that is around what goes on down there? Because we don't and nobody talks about it… I recently sat through a seminar around the menopause and a doctor said to somebody, "What you want me to do about it? It's just what's going to happen." So, I think my victory I would like to see is more support more information… You get a lot around childbirth, but then after that you're pretty much on your own and left. And nobody ever comes back and goes to it will all go back to normal?"*

9) Prevention: 4% of responses [19 responses]

People talked about prevention in relation to diagnostics and testing as well as the impacts of better diet, fitness and self-care. The recurring theme was that it's better to stay well, than to need cures to fix health issues.

- *"Breakthrough I would like to see in my lifetime is a focus on prevention rather than treatment. Because if people got the right information about nutrition and lifestyle we would not be in this mess and people wouldn't need half the medication they're taking."*
- *"More work for prevention of diseases."*
- *"Early intervention at all age groups particularly in the younger because if the younger children don't make that first change in the first step away from things like obesity. It will stay with them until they get into adulthood where they could have underlying medical underlying conditions like stroke or type 2 diabetes."*

10) Covid-19: 3% of responses [16 responses]

When we launched Multiverse Lab in Autumn 2020, we wondered if everyone would talk about Covid-19. We were initially surprised that fewer people talked about it. Perhaps people felt with the launch of the vaccine, it was being addressed. The 16 responses only include people who called for vaccines, treatments or cures for Covid. What was far more common was people talking about Covid-19 in relation to other issues: for example the impact of the pandemic on mental health and interrupted access to health or social care.

- *"Better support and access to support for children and young people for mental health services. And adults certainly on the back of the Covid pandemic."*
- *"What would you like to see a change of? A good question for a young person. I'd like to see a little bit more … coronavirus cures. Just things back to normal? Yeah. People stop dying from it. It's just awful isn't it."*

Two Themes: Poverty & Long-Term Conditions

Alongside the most talked about issues, there were 2 cross-cutting themes that kept coming up in relation to many of the different topics.

One of the themes is **poverty**. Perhaps this isn't a surprise, in a public engagement project based in the North East and Cumbria, regions that include communities facing some of the highest rates of socio-economic deprivation in England. People talked about poverty in relation to inability to afford social care, poor housing, mental health and inequality of health outcomes.

Another recurring theme was **long-term conditions**. This related to responses about issues including ME, diabetes, Fibromyalgia, MS, chronic pain, arthritis and chronic fatigue. Responses focussed on the difficulties of getting diagnoses for some long-term conditions, and also on research into improving the quality of life and treatments for multiple long-term and complex conditions.

- *"The social implications of fuel poverty and what that does for the health."*
- *"The health inequalities in this region are stark. I… advise on poverty and inequality and I can tell you that here it is quite shocking. People are suffering and all sorts of diseases that we thought had disappeared are starting to come back."*
- *"More families having to cope with multiple complex intergenerational health and social care needs but without the housing and care support needed."*

What else did we hear?

Sometimes only 1 person raised a particular topic. But this didn't make their contributions any less meaningful. People talked eloquently and movingly about the impacts of particular, sometimes rare, health and social care issues. The other topics raised, continuing in order of number of responses were:

Addiction, drugs & alcohol [12 responses], **Diagnostics & Testing** [12], **Diabetes** [11], **Diet & Nutrition** [11], **Arthritis** [10], **Autism** [10], **Musculo-Skeletal** [10], **Heart Disease** [9], **Economy, Pay, Poverty & Universal Credit [**8], **Health & Social Care Working Together** [8], **Research** [8], **Blindness & Eyesight** [7], **Built Environment, Pollution & Climate Change** [7], **Children & Young People, Youth Work & Knife Crime** [7], **Disability support & Hidden Disabilities** [7], **HIV & AIDS** [7], **Housing & Homelessness** [7], **MS** [7], **Obesity** [7], **Training** [7**], Asthma, Respiratory System & Lung Disease** [6], **Genetic Research** [6], **Neuroscience** [6], **Parkinson's** [6], **Public Consultation** [6], **Racism** [6], **Education** [5], **ME & Chronic Fatigue** [5], **Migraine** [5], **Pharmaceutical Companies** [5], **Alternative Therapies** [4], **Bio-technology** [4], **Contraception & Sexual Health** [4], **Chiropody & Podiatry** [4],

Chronic Pain [4], **Epilepsy** [4], **Malaria** [4], **Psychology** [4], **Side effects of Treatments** [4], **Waiting Lists** [4], **ADHD** [3], **Long-term Disease** [3], **Exercise** [3], **Fibromyalgia** [3], **Gender Dysphoria** [3], **High Blood Pressure** [3], **Men's Health** [3], **Motor Neuron Disease** [3], **Skin, Dermatology, Psoriasis & Scarring** [3], **Stress & Bullying** [3], **Stroke** [3], **Tourette's** [3], **Auto-Immune Conditions & Immune System** [3], **Acute Injury & Emergency Services** [2], **Antibiotic Resistance** [2], **Bowel Conditions, Crohn's & IBD** [2], **Connective Tissue Disease** [2], **Gut Health** [2], **Hearing Loss** [2], **Huntington's Disease** [2], **LGBTQ+ Support** [2], **Learning Disability Support, Equality & Family Support** [2], **Organ Donation & Transplant** [2], **Private Healthcare** [2], **Spinal Injury** [2], **SWAN & Undiagnosed Conditions** [2], **Allergies** [1], **Colour Blindness** [1], **Ebola** [1], **Hyperthryroidism** [1], **Inflammation** [1], **Incontinence** [1], **Kidney Disease** [1], **Life Expectancy** [1], **Occupational Therapy** [1], **Pancreatitis** [1], **Population Growth** [1], **PTSD** [1], **MPS (Mucopolysaccharidoses)** [1], **Palliative Care** [1], **Reynaud's Syndrome** [1], **Stem Cell Research** [1]

- *"I'd like to see the day when we can regrow nerve cells so that people with spinal injuries, like me, can fully recover!"*
- *"Something that will cure migraines. So, my personal migraines are quite debilitating… I can't drive. Being self-employed that's quite a problem. It'll last 3-4 days. It'll affect my sleep, my ability to eat... I do take medication for it… It doesn't touch It for the first few days."*
- *"The medical research I'd like to see in my lifetime is finding more people with my genetic condition."*
- *"I would like to see quicker diagnosis of conditions such as fibromyalgia, ME, MS, chronic fatigue syndromes. It takes a very long time to get diagnosed. You go through years and years of symptoms before doctors finally suggest it could be something like that. It's a matter of a process of elimination of other things rather than a test specifically for that condition."*

Who Made Multiverse Lab?

Multiverse Lab was made by Unfolding Theatre and commissioned by a consortium of partners:

- VOICE
- The National Innovation Centre for Ageing
- National Institute for Health Research (NIHR)
- NIHR Newcastle Biomedical Research Centre
- NIHR Newcastle In Vitro Diagnostics Co-operative
- NIHR Newcastle Clinical Research Facility
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- NIHR Applied Research Collaboration North East and North Cumbria
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