Greengross A4D Global Arts for Brain Health Changemakers Conversations online 2023-24

Hosted by Veronica Franklin Gould
President of Arts 4 Dementia

In association with

AGE Irrelevance

Innovative inclusive cultural and creative practice to combat cognitive challenges and rebuild identity and resilience in the community

In the spirit of the late, indomitable Baroness Sally Greengross, founder patron of Arts 4 Dementia and Change Maker par excellence, our Global Arts for Brain Health Change Maker Conversations shared insights into innovative creative health practice around the world from Christopher Bailey, Arts and Health Lead at the World Health Organisation, and Professor Brian Lawlor of the Global Brain Health Institute and leading clinicians, academics, strategists and social prescribers.

Young people with lived experience of rare dementias and of the trauma of forcible displacement and torture describe how taking up and persevering with arts activity empowers them to preserve identity, express themselves, rebuild resilience and feel welcome in the community, to continue study, work and volunteer.

We are enormously grateful to our partners Age Irrelevance, the Young Onset Network, Rare Dementia Support, the National Academy for Social Prescribing, to our distinguished chairs, speakers and delegates listening in from all over the UK, from Australia, Austria, Brazil, Cameroon, Canada, Egypt, Ethiopia, France, Germany, Ireland, India, Jordan, Italy, Malaysia, Malta, the Netherlands, Nepal, New Zealand, Nigeria, Peru, Portugal, Qatar, Romania, Singapore, Spain, Switzerland, Taiwan and the United States.

The Greengross Global Arts for Brain Health Changemaker Conversations

Abbreviations

AHP	Allied Health Professionals
APPG	All-Party Parliamentary Group
CHWA	Culture Health and Wellbeing Alliance
FAD	Familial Alzheimer's disease
FFTD	Familial frontotemporal dementia
FTD	Frontotemporal dementia
GBHI	Global Brain Health Institute
ILC	International Longevity Centre
LBD	Lewy Body Dementia
NASP	National Academy for Social Prescribing
NCCH	National Centre for Creative Health
NHS	National Health Servie
PCA	Post Cortical Atrophy
PPA	Primary Progressive Aphasia
RDS	Rare Dementia Support
SP	Social Prescribing
SPLW	Social Prescribing Linkworker/s
UCL	University College London
VR	Virtual Reality
WHO	World Health Organisation
YAD	Young Onset Alzheimer's disease
YOD	Young Onset dementia

The Greengross Global Arts for Brain Health Changemaker Conversations
Host: Veronica Franklin Gould

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1. Inaugural Conversation: Monday 4 September 2023

CHAIR: Veronica Franklin Gould, President, Arts for Dementia.
Kay Allen OBE, Campaign Director, Age Irrelevance.
Christopher Bailey, Arts and Health Lead, World Health Organisation.
Brian Lawlor, Professor of Old Age Psychiatry at Trinity College Dublin, and Site Director Global Brain Health Institute.
Thomas Kador, Associate Professor, MASc in Creative Health, UCL.
Kunle Adewale, Founder of the Global Arts in Medicine Fellowships.
Dr Bogdan Chiva Giurca, Clinical Lead and Global Director, National Academy for Social Prescribing (NASP)/.

2. Young Onset Conversation, Thursday 26 October 23

CHAIR: **Jan Oyebode,** Professor of Dementia Care, the University of Bradford.
Kate Swaffer, author, activist, academic, poet, photographer, Australia.
Keith Oliver, Alzheimer's Society ambassador, author, photographer, poet
Wendy Mitchell, author, photographer, social media champion, blogger
Chris Norris, tenor horn player in brass bands in Kent
Gail Gregory, artist and blogger
Hamaad Khan, Global Social Prescribing student champion scheme
Tessa Gutteridge, Chair, Young Dementia Network and Young Onset Dementia Programme Director, Dementia UK.
Adam Ockelford, Professor of Music, University of Roehampton.

3. Rare Dementias Conversation, Thursday 18 January 2024

CO-CHAIR**: Sebastian Crutch**, Professor of Neuropsychology, Dementia Research Centre, UCL..
CO-CHAIR: **Charlie Harrison,** Creative Consultant, Rare Dementia Support.
Helena Clarke, artist living with Post Cortical Atrophy and **David Clarke**
Chris Chadburn, living with logopenic variant PPA, and **Andrea Chadburn**.
Tony Thompson, Chief Executive, Artistic Director, Sweet Patootee Arts.
Rebecca Goldstone, Co- Director and Producer, Sweet Patootee Arts.
Monica Boulton, Healthcare Integration Lead, NASP.
Eloisa Stella, President, Novilunio, Padua, Italy.
Tiziano Tracanzan, advocate living with Young Onset Alzheimer's Disease.
Cristian Leorin, adjunct Professor at the University of Padua and the University of Modena-Reggio Emilia, co-founder and Vice-President of Novilunio.
Francesco Parisotto, living with Cadasil.

4. International Social Prescribing Champions, Thursday 14 March 2024

Dr Bogdan Chiva Giurca, Clinical Lead and Global Director at NASP launches The Social Prescribing Student Champion Scheme report *Seven Years On!*
CHAIR: **Hamaad Khan**, Global Development Officer, NASP.
Charlotte Osborn-Forde, Chief Executive Officer, NASP.
Nicola Gitsham, Head of Social Prescribing at NHS England.
Kirstie Goodchild, Social Prescribing Student Champion Evidence Lead.
Naabil Khan, Social Prescribing Student Champion Global Lead.
Alexandra Tan, Student Champion Social Media Lead.
Abbey Deguara, Co-lead, AMSA Social Prescribing Student Collective. Australia.
Maddie Maier, Chair, US Social Prescribing Student Collective, and founder of the Harvard Undergraduate Initiative for Social Prescribing.
Le-Tien Duong Bhaskar, Co-Lead, Canadian Social Prescribing Student Collective.

5. World Refugee Day, Thursday 20 June 2024

CHAIR: **Alexandra Coulter,** Director, National Centre for Creative Health.

Cornelius Katona, Medical and Research Director, Helen Bamber Foundation.
Christopher Bailey, Arts and Health Lead, World Health Organisation
Almir Koldzic, Director and Co-Founder, Counterpoints Arts

PANEL CHAIR: Professor Cornelius Katona
Daniela Nofal, Producer, Counterpoints Arts
Bobby Lloyd, Chief Executive, Art Refuge, Community Table,
Sheila Hayman, award-winning filmmaker and Co-ordinator of Freedom from Torture's 'Write to Life'

PANEL CHAIR: **Rachel Tribe**, Professor of Applied Psychology, University of East London.
Sara Green, Founder & Exec Director, Art for Refugees in Transition, New York
Dr Hanan Khalil, Associate Professor of Neurological Rehabilitation at Qatar University. Physical therapy for refugees in Qatar ,
Lis Murphy, Creative Director, Music Action International.
Ramsey Janini, Creative Producer Crisis Choirs, Music Action International.
Johanne Hudson-Lett, Artistic Director, Hear Me Out.
Phoebe Shaw, Communities Programme Manager, Untold Stories, Artcore, Derby.
Kunle Adewale, Creative technology for refugees in Bosnia, Ireland and Sheffield.

PROJEKT EUROPA / ENCOUNTER Drama for Refugees partnership
CHAIR: Alexandra Coulter, Director, National Centre for Creative Health
Maria Aberg**,** Artistic Director, PROJEKT EUROPA.
Dr Francisca Stangel PROJEKT ENCOUNTER Drama workshop facilitator.
Dr Angeliki Varakis-Martin, Lecturer in Drama & Theatre, University of Kent.

CONVERSATION **1**

Inaugural Conversation: Monday 4 September 2023

Greengross A4D Global Arts for Brain Health Changemakers Conversation 1

Inaugural Greengross Conversation (Thursday 4 September 2023)

This is the first of a series of global online Changemaker Conversations held in association with Age Irrelevance, the new campaign established by the family of Baroness Sally Greengross, to shape a new narrative and redefine life's horizons in the era of longevity. Our Conversations explore innovative ways in which people facing challenges and trauma in younger life find expression through culture and creativity to preserve their brain health, resilience, sense of purpose, identity and belonging in the community.

CHAIR

PANEL

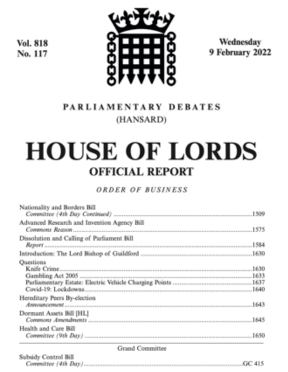
Greengross A4D Global Arts for Brain Health Changemakers Conversation 1

Veronica Franklin Gould, President, Arts 4 Dementia

Good afternoon – a very warm welcome to our speakers and delegates from all over the UK, from Australia, Austria, Brazil, Canada, Ireland, Malaysia, Nigeria, Peru, Switzerland and the United States.

Today's inaugural Global Arts for Brain Health Changemakers Conversation marks the start of World Alzheimer's Month. Our Zoom Conversation series is inspired by the phenomenal legacy of Baroness Greengross who died last year. As Co-Chair of the All-Party Parliamentary Group on Dementia and patron of Arts 4 Dementia, Sally did so much over the years to advance arts for brain health strategy in Parliament. (Hansard Debate Excerpt, pp. 86-89, 92-95 and more) It is an honour to be running this programme in association with the Greengross Age Irrelevance Campaign, and in collaboration with leading educators today – to share international practice to inspire new arts for brain health opportunities around the world.

In view of fears and stigma people feel at the thought of their deteriorating brain, both privately and in public, we refer to arts for brain health as constructive action on the part of both arts facilitators and their sensitive participants, who may be in denial of 'dementia'.



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Wednesday
9 February 2022

PARLIAMENTARY DEBATES
(HANSARD)

HOUSE OF LORDS
OFFICIAL REPORT

ORDER OF BUSINESS

Nationality and Borders Bill
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Advanced Research and Invention Agency Bill
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Grand Committee

Subsidy Control Bill
Committee (4th Day) ....GC 415

Melvyn Bragg, the broadcaster, author and parliamentarian, talks with learned passion of the role of culture to society. Arts are significant to our lives, whether singing to ease birth contractions, to please and calm our children on the school run, their singing, dancing and painting in or out of school etc, youth music, choirs and community arts hubs, arts keeping us fit, masterpieces and performances opening our minds to new discoveries. Taking part and creating, strengthens our cultural identity, relieves stress, strain and preserves our brain health lifelong.

How crucial this is for people experiencing early symptoms of a dementia – Each year there are ten million new cases worldwide, over 200,000 in the UK. Diagnosis can take years. For individuals and their partners, fear of their deteriorating brain brings immense strain, fear. The very fear, even shame that keeps them from facing others outside home. Arts involvement bridges the peri-diagnostic support gap for them and their loved ones and provides a lifeline ongoing.


A.R.T.S. for Brain Health
Social Prescribing transforming
the diagnostic narrative for dementia
From Despair to Desire:

Veronica Franklin Gould

Regular arts activity addresses modifiable risk factors for dementia and protects against the advance of cognitive decline. For example, learning music, poetry or drama, exploring works of art, finding the artist's or composer's intention, challenges the brain to create new neural pathways. Social weekly activity, music, dance, creating theatrical scenarios, connecting actively with nature and politics protects against loneliness, physical inactivity, obesity and depression. Choosing to participate empowers people to preserve interests, companionship and wellbeing together in the community for longer. It is not our ailments or medical state that define us, it is our pursuits that define and raise our spirits.

The means to connect with local opportunities has been revolutionised by the introduction of NHS social prescribing linkworkers (SPLW) to whom GPs can now refer patients from the very onset of dementia symptoms, to direct them to local arts and wellbeing groups of personal interest.

Over the next fifteen months, professors of innovative ageing and arts for health will introduce Conversations between people young and old, who will share their own experiences of using the arts to override symptoms of various dementias. They are reviving and developing new skills and their best-selling books are inspirational to others. Each Conversation will bring wider attention to a specific theme – for example, we shall hear from artists with Young Onset Dementia, followed by those with Rare Dementias.

Today, Christopher Bailey who leads Arts and Health at the World Health Organisation, will give an insight into remarkable examples of best practice. Then, in order to make social change a reality – our focus will be on multi-disciplinary education, with Professor Brian Lawlor of the Global Brain Health Institute, Dr Thomas Kador who leads University College London's Masters in Arts and Sciences in *Creative Health*, Kunle Adewale of Nigeria, founder of the Global Arts in Medicine Fellowships and Dr Bogdan Chiva Giurca, Global Social Prescribing Alliance development lead and founder of the Global Social Prescribing Student Champion Scheme.

We are enormously grateful to our speakers today whose guidance inspires best practice in arts for brain health the world over.

And to introduce the Greengross Age Irrelevance campaign, I have great pleasure in welcoming Kay Allen.

KAY ALLEN is Age Irrelevance's Campaign Director, formerly served on the Disability Rights, the Equality and Human Rights Commissions. Perfect. Age Irrelevance is all about inclusivity – Kay, do tell us about your Mission.

AGE IRRELEVANCE

Kay Allen OBE, Campaign Director, Age Irrelevance

Thank you so much, Veronica. I'm thrilled that we've got a lecture in the name of Sally up and running. I am certainly not an expert in your amazing field with the speakers that are on the call. But just to give you some context: Sally was an incredible person. Some of you may have known her, but she was one of the world's leading advocates on age as a massive subject. In the United Kingdom, she was made an Honorary Fellow of the Royal Society of Medicine. She was passionate about inclusivity once people had had their dementia diagnosis.

Sally Greengross and the intergenerational origin of Age Irrelevance

I had the great privilege of working alongside Sally on many boards and serving as Commissioners. Sally was always ahead of her time. Thirty years ago, she talked to me about why there was discrimination, that we must remove the age barriers. Two years ago, just before Sally was diagnosed with cancer, she came to me and said she had this last big idea. Her last big idea was around Age Irrelevance for society. She wanted age not to define us and to put us in those silos. She wasn't talking about older people – she was talking about every age and how every age can benefit from those intergenerational connections and how we can look at the stages of our lives as we move through it.

Rewriting the play

She had a great analogy and a great story. She said, 'Imagine you were in a play and you were two weeks from going on stage and the producer and director came to your cast and said you have to stay on the stage for an extra 40 minutes. Do you just lengthen the final act? Do you add in a few more scenes? Or do you rewrite the play?' Sally wanted us all to rewrite the play. Because imagine if we're all now moving into that era of longevity, we're living to the 100-year life. The 100-year life is going to become our normal and the four-generational family – it's becoming the normal, certainly in the UK and in other countries.

How do we change as society?

Sally was a great parliamentarian and she believed passionately in policy and Governmental changes. But if we are going to live for 100 years and have four generational families, she knew that that would have massive impact on society. It would impact on how we save for our pension. It certainly will impact on age- appropriate housing. And, of course, it has massive impacts as we all age and live for longer. She wanted us to age better.

How best to benefit from the gift of time

She wanted us to think about the 100-year life as that amazing gift, the gift of extra time. And so, she wanted me to launch a series of challenges, challenges towards us as individuals. What will we do, our gift of extra time? How does society benefit from our gift of extra time? What Government is doing Sally was fiercely against. All they're doing is stretching one of the acts within that play. They're making us work for longer. They're making us stretch our pensions out for longer.

Employment, lifelong education and living longer better with dementia

But what Sally wanted to do was rewrite how we perceive and look at work, how we have a relationship with our employers, dipping in and out, multiple careers, different pathways. But in order to have different pathways at work, we need a different approach to lifelong education and we certainly need a different approach to pensions. The idea of us living longer for better, as we know that dementia is becoming more prevalent and we are seeing people living longer, they're living longer with dementia.

I know from my own family story that my dad was born in 1920 and he did what Government expected him to do. He had a good education, he had a good job, and he had a job for life. He started as an apprentice, he retired and he died seven years later with enough money in his pension. So my dad did what the Government of the day expected us all to do. My mum, on the other hand, my mom was a fearsome lady and always bucked the trend. She lived till she was 98 and she lived well with dementia for nine years. I know from my own personal journey with my mum and dementia, how art and music really kept her engaged. She could remember every word to every hymn that she'd ever learnt in church, despite the fact she couldn't remember my name.

Age Irrelevance Campaign, championing organisational strategies for social change

So the Campaign, just to close then, is about finding amazing ambassadors, people who are passionate about all areas of society, not just finding amazing ambassadors who are well connected. The second part of our strategy is to organizations that are going to deliver change, to deliver the Mission to take age out of the equation, to stop us putting people into silos of age and defining us by the number of birthdays that we've had, but rather look at everybody as a generating age and a purposeful age.

I'm delighted that Veronica approached us and she's brought Arts For Brain Health on board as a changemaker. So these lectures and the evidence that you all collate over the next two years will form part of our evidence reporting on our Changemakers. Because the third element of our strategy is to capture the examples and the evidence of Age Irrelevance.

Action – removing barriers to society – enabling positivity and optimism

What Sally was really clear about is that this campaign is not about research. She created the International Longevity Centre to do that research. This campaign is about action. This campaign is about removing the barriers to society. But more importantly, this campaign is about positivity and optimism. Sally didn't want me to mention the word ageism discrimination. She didn't want the language of the tsunami of old people heading towards each country as a problem. A problem and a drain on the NHS, a problem and a drain on our national health and on our pensions and our tax system.

Need to redefine longevity, amazing gift of extra time, positive benefit to society, personal independence creating savings to the NHS and care system

On the contrary, the Age Irrelevance campaign is to say, how do we define the longevity and the gift of extra time as an amazing gift back to society? And how do we add those benefits back onto the balance sheet of positivity in each of our countries? And that's where I hope that the lectures that Veronica is doing will give us that evidence. Because if you can show how you can help people live well with dementia for a long time, think of the savings that you will make to the NHS, think of the savings that you would make to the care home system if people could live independently with their families for longer, with your amazing support.

Age Irrelevance core debate at Anthropy 2023

The Age Irrelevance campaign is going to run hopefully for two years, featuring in housing conversations, education conversations, work conversations. I'm delighted to say that Age Irrelevance will be one of the core debates at this year's Anthropy Conference in the United Kingdom at the Eden Project in Cornwall.(1st-23rd November 2023) So we are leading the way to say how do we::

- Deliver brilliant age inclusivity?
- Remove the barriers?
- Create a new narrative for people around the world to talk about longevity as a positive optimism rather than a problem that has to be solved.

Thank you, Veronica, for creating these debates and I look forward to seeing the results and the evidence of the debates as they unfold over the next two years. Thank you very much,.

CHAT
Michael Blakstad Does the medical/clinical effect on the brain of stimulation by arts &c come into the thinking behind the campaign? **Veronica, Arts 4 Dementia:** As well as published studies referred to in our *Global Social Prescribing: The A4D Arts for Brain Health Debate*s (2023)
A.R.T.S. for Brain Health: Social Prescribing transforming the diagnostic narrative for Dementia: From Despair to Desire, (2021), we are planning a Longitudinal Study with UCL East (2024-28) to ascertain the clinical effects, of engaging with arts.

Veronica Franklin Gould, Chair Thank you very much, Kay. Now there's a challenge. Our purpose is lifelong education. These programmes, the involvement with the arts, is to continue learning and discovering. The great thing is intergenerationality the old, educating the young and the young inspiring the old. And so indeed, society will benefit by the aging population through their involvement with the arts.

I look forward very much to hearing now from Christopher Bailey.

CHRISTOPHER BAILEY is the Arts and Health Lead at the World Health Organization and a co-founder of the Jameel Arts and Health Lab. The lab focuses on the evidence base for the health benefits of the arts by building up a global network of research centres to look at effective practice as well as the foundational science of why the arts may benefit physical, mental and social wellbeing - Truly rewriting the play, isn't it - to support underserved communities around the world. Chris, it will be fascinating to hear your healing arts highlights. o support under-served communities around the world. Chris, it will be fascinating to hear your healing arts highlights

Christopher Bailey, World Health Organisation (WHO)

Well, I hope so! As you and Kay were talking, I was thinking about my grandfather, who died many years ago, but he lived to be 100.

Strange sense of discovery

In the last years of his life, he was like a lot of older people, feeling a little lonely because he was outliving not only his friends, but the children of his friends. That feeling of isolation was exacerbated by the slow eroding of his faculties. He couldn't hear as well, He couldn't see as well and his memory was failing. One day I was talking with him and I noticed he was in a particularly good mood. I asked him what had changed? 'What made you into such a good mood?' And he said, 'Well, you know how I've always loved mystery stories. He had this amazing collection of mystery stories on his bookshelf. Well, I suddenly realized that with my failing memory, I don't remember the endings to any of them. So I'm going to spend the next few years of my life rereading them all and being surprised.' I loved that because it was a way of getting back to that sense of discovery and that sense of opportunity and surprise.

WHO UN Decade of Healthy Ageing

At WHO we with the UN declared this decade as the decade of healthy ageing. In 2020, there was an interesting milestone for our species. For the first time, the number of people who are 60 years and older outnumbered the number of people who were five years and younger, and that was kind of a tipping point in this demographic shift. As far as WHO goes, one of the things we're interested in is not just treating the conditions of an ageing population or simply lengthening the lives of people, but actually looking at the quality of that life within the life course.

'Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity'

It gets back to our fundamental definitions of health and mental health. The WHO definition of health is from our 1948 Constitution, it is not merely about the absence of disease and infirmity, it's about the attainment of the highest personal level of physical, mental and social wellbeing. In terms of healthy ageing, that means at any point in the life course. So if you're an older person, what can be expected to be your highest physical, mental and social level of wellbeing? In our definition of mental health, it's in some ways ancilliary to the definition of health itself. Like the definition of health, it's not merely about the absence of mental illness or mental conditions or their symptoms. It's about your ability to cope with the everyday stresses of life.

Achieving highest individual potential, being productive, participating – to thrive

It's about being able to achieve your highest individual potential in terms of your skills and faculties at that point in your life course. It's about being productive. It's about participating in community. It's frankly about acknowledging moments of joy. If you can do all of these things, you are mentally healthy, regardless of what diagnosable conditions you may or may not have. I think that's important to remember because that opens up, for one thing, a different way of measuring health. It's not just about what deficits can be alleviated, it's about what assets can be brought to the table. That, I think, is the whole movement behind the Healthy Aging campaign, looking at the assets, looking at not merely surviving, but thriving.

Arts to promote health and wellbeing

Which brings us to the use of the arts in this context. People are surprised that WHO has an arts and health programme, but actually we've been involved in the arts from the beginning of our history, but usually in the context of health promotion. But even when you look at a health promotional context using the arts, other things begin to emerge. I'll give an example.

Playwriting in India to raise awareness of health information

There was a programme in Mumbai, in India, of trying to educate women in the Dalit community about access to medical care for women. The idea was to have the women themselves write a play and be able to show this play to the community, to help encourage the knowledge of how to get health information, where to get it, etc. In the writing meeting, this group of women were gathered around and pencils and paper were passed out to each of the individuals. An interesting thing happened because before even any word was put to paper, a change began to happen.

- There was one older woman who lifted up the sheet of paper and asked, ‘What am I supposed to do with this?’ And we said, ‘Well, you're supposed to write down your ideas for the play.’ And she said, ‘Why would I ruin a perfectly good piece of paper by writing on it? I'm a fishmonger. Paper should be wrapping fish.’ That was her perspective.
- Another woman was clutching the pencil, and tears were streaming down her face. When we asked what was wrong, and she said that this was the first time she had held a pencil since her marriage at 14 to an older man who then forbade her from ever writing again. So just the act of writing itself became a change for her, a transition.

Carl Jung, on loneliness

It got me to thinking about the nature of communication and the healing nature of communication, regardless of what health content may or may not be communicated; and it brought me to a quote that I've often used in these conversations by Carl Jung, who said, *Loneliness is not the absence of people. Loneliness is the inability to express what matters to you most.* In the latter third of our life course, it's that inability to express that becomes so painful. And that inability can be aggravated by a physical disability, by our failing senses, our hearing, our sight, our ability to speak or even having someone to speak to, of isolation, of friends disappearing, of a feeling of irrelevance that the stories that you have to tell are not wanted or felt to be interesting by a younger generation.

So how can the arts and creative expression address things like that? Well, I think it can address it on so many different levels. I'll give one concrete example. I've been involved with Renee Fleming in helping organize with the LA Opera, LA Arts and Health Week for the last two years.

Korean Kimchi Festival in Los Angeles

We had one event in Koreatown in Los Angeles where the local community centre had shown through a survey that the two population groups that were most affected by the pandemic in terms of feelings of isolation were the elders and the teenagers. And when they brought in professional help for psychosocial support, it was the older generation that rejected it, that they were too proud. They didn't really understand what was being asked of them, what help was being offered. So a different tack was used. The elders were asked, ‘Well, what is important to you? What is a cause of concern or anxiety that we can talk about?‘ And they said that the young people in their community weren't learning the food ways of being Korean. What they then did was created this kimchi festival where literally, and I saw it, hundreds of people, the elders of the community, would bring in the younger people and physically show them how to make kimchi. They would put their hands would join together in the bowl. The older people would take out their cabbage leaves and fold in the spices. Their hands would touch. And as that knowledge was being transferred, there was a physical connection, but also a connection of stories. Stories began to flow out of their aunt in Seoul who had this recipe. Pretty soon there was this joy and the sense of community that was emerging. And we saw in the surveys following an added ability to cope with the pandemic, a sense of hope in the future, a stronger sense of community on all sides. It was a measurable change. So I think when we think about the WHO definition of health, of physical, mental and social wellbeing, the arts have a lot to say in all aspects.

Carl Jung on meaning in old age

There's a second quote of Carl Jung that I think is particularly important for the last third of the life course discussion. That's when he said, *Meaning is what allows us to endure*. I think for many people who are facing the loss of their faculties, the loss of their friends, increasing isolation and a growing awareness that death is not only inevitable but may come soon, there is an instinct, a reflex, to try and find some kind of authentic personal meaning in that passage. And it's the arts that can allow us to find that and make it true for ourselves and give that portion of our life meaning, not just for ourselves, but for our loved ones and our caregivers as well.

Role of arts to enable creative expression in older age – enobling us all lifelong

There's been a tremendous amount of research done in the beginnings of life and the formation of personality and intellect in the first five years, in the teenage years, and how the arts can play a role in that in creative expression, but comparatively less for the end of life. I think here's where this opportunity comes from measurement as well, to see how using tango in South America can help Parkinson's patients express themselves. Maybe not roll back the disease, but to find a way of expressing and of connecting how programmes and museums can bring in dementia patients and through curated conversations, find those moments of connection, those moments of memory, those moments of grace, of reconnecting to each other, to the world and to themselves. I think when we can participate in such things, it not only gives a better quality of life to older people, regardless of whether they have a debilitating condition or not, but in fact it ennobles and raises up all of us because we are all part of one human family. That, in the end, I think, is the blessing of the arts being able to help us find the authentic meaning. It may not cure our conditions, but it certainly helps us curate our lives. Thank you very much.

VFG, Chair How important a sense of meaning is. Chris, thank you so much. Arts helping people reconnect to themselves, to the world and to others, and arts helping us to express ourselves. And dancing the tango in South Africa for Parkinson's also dance for Dementia helps people to express themselves. Thank you, Chris, very much. To hear this from you is extremely special.

CHAT

www.ageirrelevance.com

Jonathan kaye: How do people with ideas and enthusiasm connect with people of influence, to bring about change?

Kay Allen: Great question Jonathan - The age Irrelevance Campaign sees itself as a connector joining up people who together can collaborate to deliver change

Kunle Adewale: with ❤️

Furrah Syed FRSA Thanks Chris for such an inspirational talk. I agree with you that we are all humans who can support each other to live a long, healthy and happy life.

VFG, Chair And now I'd like to introduce to Professor Brian Lawlor.

PROFESSOR BRIAN LAWLOR is Professor of Old Age Psychiatry at Trinity College Dublin, and Site Director of the Global Brain Health Institute. He is a geriatric psychiatrist specialising in dementia, late-life depression, loneliness and brain health. His research interests range from early detection and prevention to evaluating new treatments for dementia. Brian's transformation of the narrative of dementia from one of Tragedy to Hope inspired our entire programme and that of the Global Brain Health Institute's Atlantic Fellows for Equity in Brain Health, who will be the subject of our next year's World Alzheimer's Month Conversation.

Brian, your Atlantic Fellows come from a mix of disciplines and from all over the world – could you give us an insight into the GBHI Fellowship programme . . .

Professor Brian Lawlor, Global Brain Health Institute

Thanks Veronica. I'm delighted to be here and talk about Global Brain Health Institute and I'm completely at one with Chris and with Kay with regard to the need to reframe, rethink how we see issues of aging and dementia, really reimagine and look at them in a different way and in a creative way. I think the arts are core to how we may be able to do this.

The need to rethink, reframe dementia to improve life for people with dementia

In our approach to dementia, we very much need creative solutions that go beyond the existing professional silos if we are to overcome the great fear and stigma that is preventing us from taking effective action for dementia right now.

For people over the age of 50, dementia is feared much more than cancer and stroke. There's very much a sense of hopelessness and despair when it comes to talking about dementia, a belief that there's nothing that can be done and that it's going to happen to us anyway as we age.

But the reality and the truth is that dementia is not inevitable, that there are many social determinants that can be addressed, that risk factors can be reduced, new medications and treatments are becoming available and can be developed, as we saw in the case of cancer; and that rethinking dementia, reframing dementia from the perspective of brain health allows us to take action to improve the health and wellbeing and quality of life of people living with dementia right now.

Dementia too siloed across professions and disciplines

The field of dementia is very siloed across professions and disciplines. There's a lack of awareness about dementia among the lay public and healthcare professionals alike, and stigma. Stigma is very much rampant. So we need this reframing, these new perspectives and approaches to tackle the issue. That's where the Global Brain Health Institute and the Atlantic Fellows for Equity in Brain Health programme comes in.

Global Brain Health Institute

GBHI was founded in 2015 from a generous grant from a philanthropist to bring this new perspective and approach to address the many inequities across the life course that cause dementia and to take a transdisciplinary approach to changing public policy and practice ,so that the lives of people at risk of dementia and those living with dementia and their care partners would be improved.

Need to change the narrative of dementia from Tragedy to Hope

Central to this is changing the dementia narrative from tragedy to hope and reframing dementia from the perspective of brain health, shining a light on the many upstream inequities and social determinants that influence the development of dementia.

Taking a brain health approach to dementia emphasizes that there are ways that you can protect your brain, reduce risk to your brain, and that you can improve your brain function even if you have dementia. This perspective, I believe, is crucial if we are to address and overcome the negative attitudes that permeate society around dementia, its diagnosis and its treatment.

Art is the highest form of Hope

Arts and creativity are very much part of this story, as you've heard from Chris. Arts, music, culture are an important part of the framework of hope for dementia This has been put beautifully by many people, but particularly by Gerhard Richter, the great German visual artist, who said, *Art is the highest form of Hope*.

GBHI Atlantic Fellows for Equity in Brain Health Programme

Let me tell you a little bit more about the structure and organization of the GBHI and the Atlantic Fellows for Equity in Brain Health Programme. GBHI has two founding sites. One in San Francisco at University of California, and one at Trinity College, Dublin. GBHI's mission is advanced in three main ways:

- Firstly, through advocacy
- Secondly, through knowledge sharing and education
- Thirdly, and most importantly, through its Fellowship training programme

Fellows from all branches of medicine, social sciences and the arts, from all over the world

This Fellowship has been created to fill a gap to train interprofessional leaders in the area of brain health and dementia prevention from all around the world, but particularly coming from low- and middle-income countries. Our Fellows train together in both Dublin and San Francisco in a one-year residential programme.

A very important and novel aspect of the Fellowship is that these Fellows come from all branches of medicine. They come also from psychology, from the social sciences, from engineering, from architecture, and of course, from the arts. I'll tell you more about that later. Diverse perspectives are encouraged so that we can arrive at innovative solutions for brain health and dementia prevention.

We've just started with our eighth cohort in Dublin and San Francisco. We've now over 200 Fellows spread all over the world in over 40 countries.

The Training Programme

We have four pillars to the fellowship learning experience.

- First of all, we have a taught curriculum.
- Secondly, fellows are exposed to clinical and lived experiences.
- Thirdly, there's a faculty mentorship programmea and then leadership and skills training.
- Fellows also have an opportunity to apply for pilot funding to carry out a project in their home country on their return to help with their transformation in their local region or community.

The programme and training is very much values-based and strongly emphasize the incorporation of values of authenticity, fairness, openness, respect, courage and empathy at all times. The taught curriculum during the one-year residential time here is a mix of scientific and clinical topics that includes health, economics, policy, ethics, epidemiology and arts and creativity.

Community networking

Following the one-year residential programme in California or Dublin, Fellows join our global Atlantic community as alumni and are supported by GBHI as they begin to transform back in their local community. A key part of what we offer here at GBHI is this strong sense of community networking and support that continues throughout the Fellow's professional life.

Arts and artists in collaboration with scientists and physicians

So now let me focus on the incorporation of arts and arts methods into the Fellowship programme, which we've worked on intentionally over the seven to eight years that we've been in operation. At GBHI, we embrace arts and creativity for brain health as we firmly believe that we need arts science and a co-creative collaboration with people living with dementia to change the Tragedy narrative of dementia to one of Hope.

Arts and creativity are a core part of the Fellowship taught curriculum. A significant proportion of our Fellows that train at GBHI come from the arts, humanities and the creative space.

As part of the Fellowship, artists and creatives interact and collaborate with scientists and physicians to learn how science can inform their practice and how arts and creativity can help transform the scientists and the clinicians' approach to improve outcomes for people living with dementia and for their caregivers. Creative pedagogy is used to stimulate innovation, open discussion and to imagine new solutions and approaches.

Examples of how Atlantic Fellows have used arts and creativity to enhance connection and engagement include:

- Grainne Hope one of our Fellows here, who has a programme of cultural engagement with professional musicians to improve wellbeing and brain health for people living with dementia in nursing homes.
- Aline Haas. She's a professor of dance at the Federal University of Rio Grande do Sul. ***Porto*** Alegre in Brazil who employs various forms of dance, including Amazonian dance, to improve function and wellbeing in people with early Parkinson's disease.
- Alex Kornhuber is a photographer from Peru who creates photographic images to chronicle the inequities of ageing in his home country and help provide meaning to what it's like to experience aging in those circumstances.
- Atlantic Fellow and French neurologist Eléonore Bayen's creative cartoons educate young children about brain health, and they've been translated into multiple languages and adopted for use in French schools.

CHAT

sharifah tahir Thank you for this session. Grateful if you could share in the chat the examples just mentioned in the talk, especially the cartoon for teaching children about brain health. Many thanks. **Kunle Adewale** ❤️ **Brian Lawlor** MyBrainRobbie.org **sharifah tahir** I googled quickly. Fantastic! Thank you. If you go to GBHI Fellows' Directory you will find examples of what the Fellows are working on, including MyBrain Robbie, Music Health Ireland, Arts in Medicine

- Dominic Campbell has created international networks for arts and brain health and produced Creative Brain Week, an amazing platform that showcases the power and impact of the intersection of creativity, brain health and brain science.

Importantly, arts creativity can be used as a powerful tool for inclusion, for people living with dementia. And this has been captured beautifully in the words of

- Kunle Adewale, who you will hear in a moment, an Atlantic fellow from Nigeria who said that 'When I engage with people with dementia, there is a joy that transmits the sense of connectedness through creativity, that helps them express themselves.'

So arts and creativity can build brain health and wellbeing and help turn the fear and stigma of dementia inside out.

Bringing arts and science together to advance research and inform policy and practice

But we need to continue to bring arts and science together for brain health and advance the research around both how arts and creativity work in the brain and the evidence base of the effectiveness of arts and creative interventions on wellbeing and quality of life, so that we can better inform policy and practice. Again, this is very much how we're behind Chris's initiatives at the WHO. This is very much a core part of the mission and vision of GBHI and the Atlantic Fellows work for the Brain Health Fellowship training programme.

So if you work in the creative space and have a passion to change the narrative around dementia, improve brain health in your community, region or country, or if you know of someone like that, we'd love to hear from you at GBHI. So please, please get in touch with us at WW gbhi.org and consider applying to become an Atlantic Fellow for Equity in Brain Health. So, thank you very much. I'll hand you back to Veronica.

Global Brain Health Institute Atlantic Fellows for Equity in Brain Health programme

Application Deadline **25th September 2023**

Letters of support Deadline 28th September 2023.

VFG, Chair Brian, it's always an utter inspiration to hear from you and how brilliantly bringing together creativity and science for better life and fusing them together for change of policy strategy, and you do it par excellence. And we owe you a lot for your inspiration, and we look forward to hearing more in the discussion.

VFG, Chair I would like now to introduce Dr. Thomas Kador, who leads the MASC in Creative Health programme at University College London. His research and pedagogical interests include object-based learning, culture, health and wellbeing, public and community based approaches to heritage. The Creative Health MASs is creating a new generation of socially engaged scholars and practitioners to meet the needs of a changing health, social care and voluntary third sector where personalized care, a focus on health inequality and the patient experience are mainstreamed into public health. As this programme is the first of its kind in the world, both in terms of the qualification Masters in Arts and Sciences and the academic field of study, creative health. It will be fascinating to hear from you, Thomas.

DR THOMAS KADOR leads the MASc *Creative Health* programme at University College London. His research and pedagogical interest include object-based learning, culture, health and wellbeing, public and community-based approaches to heritage.

UCL's Creative Health MASc is creating a new generation of socially engaged scholars and practitioners to meet the needs of a changing health, social care and voluntary third sector, where personalised care, a focus on health inequity and the patient experience are mainstreamed into public health. As this programme is the first of its kind in the world, both in terms of the qualification (Masters in Arts & Sciences) and the academic field of study (Creative Health), it will be fascinating to hear from you, Thomas

Dr Thomas Kador, Associate Professor, Arts and Sciences, University College London

Thank you so much, Veronica. Thanks for inviting me and it's really great to follow Kay and Christopher and Brian. A lot of what speakers have outlined really chimes with what we do on the Masters in Creative Health, albeit that the Masters is not specializing in ageing, in older people, in dementia and brain health. It's a broader church than that. But I think it relates really nicely to things that previous speakers have said, especially what Christopher said is very relevant, but some of the things that Brian has just talked about with the Global Fellowship programme and also to what Kay spoke about in relation to how do we change the perspective that people, the population more broadly, have on ageing.

Need to break free from 20th-century perspective

My take on this is that we very much and if you look at this room here, this virtual room, our various ages, I think all of us, pretty much today's professionals, today's leaders, if you want, in different settings and so on, very much have a twentieth century perspective on ageing, as they have a twentieth century perspective on so many things. What we really need is to think about the next generation of people that come with a hopefully very different perspective rather than instilling that dominant paradigm of a job for life and what life means and all those issues and what a good life means and a long life means. So I think that we need to break out of the 20th-century perspective.

MASc Creative Health – approach to health, illness and wellbeing – co-production

This is part of what we are trying to do on the Masters in Creative Health, to think about health and illness and wellbeing in a new way, in a different way, and in a way that as the educators we do not necessarily have the answers for – in a more open way that's meant to be coproduced between our students and the members of the community and organizations that work on that interface of art, culture and health. But let me go back one step and just tell you a little bit about the MASc. Veronica pretty much summed up really nicely with that strap line of what the programme is about.

Creative Health

I suspect I'm preaching to the choir here, that you all know the term Creative Health and what it may mean, but I'll give you a brief definition, which is essentially taken from the All Party Parliamentary Group on Arts Health and Wellbeing Inquiry report in 2017 that came out six years ago, that's also been already been mentioned by Kay earlier – creating the conditions and opportunities for the arts, creativity culture, and the modifications and nature to be embedded in the health of the public. What we mean by that in a nutshell – two things already mentioned.

Rights-based equal access to health

One is tackling the endemic health inequities that are out there and that are growing in many ways. It's interesting, we're talking about life beyond 100 years becoming the norm. At the same time, if you look at the Central Statistics Office figures in the UK, actually, life expectancy post COVID has gone into reverse. Hopefully, this was a bump in the road and that it will increase again. But people are dying younger now than they did five years ago – that's a serious issue with health inequities. So that's one aspect we want to address, that access to health is as equally distributed as possible and on a rights-based level – it's a big ask.

Asset-based approach

In relation to that we are focussing on asset-based approaches, as Christopher mentioned, thinking about the assets not in the financial sense, but in a social sense. The resources, opportunities, facilities that are already out there in communities that could be put to work in support of the health of the public. So how do we bring those two together, the inequities on one hand, addressing those through the assets that are actually already there within the community. So that's what we are working on, on the MASc– it 's very broad in that sense.

Timeline

Every student comes with their own set of interests and the structure is usually a one-year programme, or two years for part time students.

Content, arts for health modules

Half of that programme is a taught component where we have some core modules cover the basics of creative health. What is it about, what are the different interventions that are out there? And what's the evidence for some of those interventions, whether it's nature-based working, gardening, the arts – performing arts, as well as visual arts and health museums and cultural heritage. So different approaches and their health benefits, and also thinking about methods and how do we assess the benefit of these aspects.

Interdisciplinary approach

Then also a core aspect is thinking about interdisciplinarity and how we need interdisciplinary approaches, how we need to break out of the silos in order to address the problems of the present and the future. These core modules make up half of what we do

Community-based dissertation

The other half is made up by a community-based dissertation, a project where students work in collaboration with a community partner.

I just want to finish with two examples from the current year's dissertation projects that are in a way closely related to the conversation today.

- One is a cognitive stimulation therapy (CST)- based research project. I know it's controversial within the field of dementia research, but it's one approach and that's what the student is doing. So, they're working together with a large UK museum combining object-based approaches to CST, the cognitive stimulation therapy with dementia patients, to assess what benefits the object-based element in a museum setting has in a CST framework. That project is just about finishing up and it's really exciting.
- What Matters Most – end of life The second one, also reflecting Christopher's discussion about the Korean people in California, is that the question most important to them, is actually what matters to them most in their life. We have a student who works with an organization called What Matters Most, who are working on conversations about what matters in relation to thinking about end of life and what matters to people. Our student has taken that completely out of the current box that it's in, largely focusing on older people and brought it into primary schools and talking with teenagers about what matters to them and young adults as well as older people. Again, very interesting findings.

So these are the kind of projects where we're working with a partner organization and trying to shift the paradigm, trying to ask new questions. Then if students are interested in pursuing that, we also have a PhD programme. Currently, for example, I'm co supervising two PhDs on dementia research in a museum setting. So these are some of the things we do in that field of cognitive health and dementia. But as I said, the master's is a much broader church.

UCL MASc Creative Health

Application: Register Interest Deadline: 31 March for enrolment in September

VFG, Chair Thank you very much. Thomas, that's extremely interesting. I must admit I was very impressed by your students and also by going on one of the projects. The line absolutely fascinating about the brick, taking What Matters Most to school, focusing on older people and taking that into schools. I think that's very age irrelevant subject. Very, very interesting, making them wear at an early age and therefore creating greater understanding. And I would love to talk to you more about the PhD programme for dementia research. So, so much to talk about in the conversation afterwards.

CHAT

Thomas Kador https://www.ucl.ac.uk/arts-sciences/study/postgraduate-study/creative-health-masc
Iva Fattorini 🙏

VFG, Chair Now I would like to turn to Kunle Adewale. Kunle, how your Arts in Medicine Fellowships have grown.

KUNLE ADEWALE who is himself a Senior Atlantic Fellow for Equity in Brain Health, having trained at GBHI's San Francisco campus, founded the Global Arts in Medicine Fellowships, originally in Nigeria. Now based in Manchester, Kunle is a Multimedia Artist leveraging the fusion of arts and creative technology for Seniors' brain health. He is Curator and Development Lead for the Global South & Arts Health Week and – of particular interest today - founder of the Global Arts in Medicine Fellowships, involving over 1,000 students and professionals from 50 countries in Africa, Asia, Europe, the Middle East, and the Americas. Kunle, welcome! Do tell us how your splendid cross-disciplinary Fellowship operates, how your Fellows are collaborating around the world to devise arts programmes to help people preserve their brain health

Kunle Adewale, Founder, Global Arts in Medicine Fellowship

Thank you so much for that wonderful introduction. I just want to just give a shout out to Chris, Dr Brian, and also Thomas for the wonderful presentations. I'm the founder of the Global Arts in Medicine Fellowship programme (GAiMF), and also a Senior Atlantic Fellow for Equity in Brain Health.

GAiMF Collaborating for Change

The culture of collaboration is at the core of GAiMF because, again, when we think about change, change begins with collaboration. Alone we can do so little, but together there's so much more we can achieve. And in so doing, we try to introduce a learning opportunity for professionals and students in Africa, in Asia, Latin America, Europe, and other parts of the world to start thinking of how to collaborate and develop intervention that they can use to support the aging population, people with mental health disorders, and other health challenges as well.

GAiMF was founded primarily in the year 2017-18 through the grand support of the USA Department and also the US. Embassy in Nigeria to be able to provide platforms where young people and the older generation can connect and begin to have conversation and collaborate to create change that can inspire positive impact in their communities From starting that programme in Nigeria, we've seen how that programme has really scaled and grown to impact more generations and populations across demographies and across continents.

GAiM Fellows

Many of our Fellows come from the field of media and communications, some come from the field of art, some are musicians, some are journalists, others are policymakers, even government officials.

Intergenerational, international, interdisciplinary

It is very interesting to see how many are young people because again, the Fellowship is intergenerational in design. It's also very international and interdisciplinary in its design. We understand that the solution to the world problem cannot be solved by one single person or one single discipline.

It takes a village to bring change to the world.

What is happening now is the GAiMF is actually creating that ecosystem, a network, a village of changemakers who are actually creating a positive impact by leveraging artistic interventions to support the populations in their communities. We've seen incredible change in different communities in Nigeria, in Kenya, in Botswana, in South Africa, and in other parts of the world, even here in the United Kingdom, where Fellows have started collaborating on projects cross-culturally and cross-continentally and cross-disciplinary, to see how they can be able to bring joy to the ageing population. There's so much stigma around dementia, around Alzheimer's disease.

Creativity to reduce stigma associated with brain health disorders

One of the things our Fellows have been doing over the years is to continue to use creativity, to be able to reduce the stigma associated with brain health disorders, by bringing in the virtual reality creative therapies, by bringing in music, and all forms of art.

Medical students delivering arts programmes for patients

Most importantly to see even our medical students are recently plugging into creativity, plug into art in health programming, to be able to deliver programme while they are in college, but also delivering programmes for patients in their institution, teaching hospitals. We think this is part of the things we are looking forward to seeing, to see how change has been activated, how change has been sustained through collaboration with Fellows.

Collaborating through social media

During the program, usually they get to collaborate using leveraging social media, like WhatsApp platform. Fellows are usually grouped because of the large numbers of people who get to join the Fellowship from around the world.

What we do is to create smaller regional groups so that Fellows can talk between each other, start having conversations around the problems within their communities. That way they have easy communication access, easy for engagement, for change, for improvement, and to see what can happen in the long run and in moving forward.

GAiMF Timeline

The Fellowship runs for a period of three months, twice a year. So, we have six-month calendar in every year where Fellows get to learn for two hours, virtually every Sunday

Ideation

During this course, Fellows have the opportunity to be able to present what we call ideation, to pitch the idea based on what they have actually discussed, based on their conversation.

GAiMF bringing communities together

Many of these Fellows have never met before. It's interesting to see how GAiMF is bringing communities together, closer together. Even though people live very close, they are separated by their discipline, their cultural practice. But the GAiMF is bridging this gap such that Fellows can have access to resources they need to support the population in their communities.

GAiM Fellows

- Tobi Sodimu founds Origami Society Nigeria One of our GAiM Fellows started using origami. Many of us, when we were younger used paper to make kites. We made paper kite, right? But it's interesting to see how one of our Fellows starts using paper folding to support the brain health of the elderly people in Nigeria. His name is Tobi Sodimu and today he's founded what is called Origami Society Nigeria, being inspired by the ecosystem and the network presence of the GAiM Fellows. Now he has created a sub-community where he's training young people, gerontologists, geriatricians, and brain health advocates on how to use origami paper folding, to be able to bring joy to the elderly people in Nigeria.
- Rebecca Gill Another instance is another fellow who is domiciled here in the UK who is using creative therapies – VR therapy – to support the elderly people who are actually dealing with cognitive impairment. Rebecca is using technology to be able to bring the aging population together by providing a transformative therapeutic experience. Through VR, she is giving them opportunity to
  - Travel to their choice of destination in the world.
  - Experience paintings such as that of Van Gogh or Michelangelo.
  - Dance and move their bodies in a way they've never done for a long time.

This is the essence of the Fellowship, such that people can leverage resources from art to technology, from technology to other disciplines to see how we can fuse these different disciplines together such that it can become something that can bring positive change or changes into the lives of the vulnerable population.

I myself as a young artist and multimedia practitioner over the years have continued to leverage creative technologies to support the brain health of ageing population in Nigeria, in Ireland, and also here in the UK, also in the United States

The GAiMF programme usually runs during summer and during winter.

Over 500 people apply to the Fellowship from 28 countries around the world. In the six years since the GAiMF was founded, the Fellowship has grown to over 1,000 applicants from over 50 countries.

Fellows give their services as volunteers

The Fellowship is not funded by any corporation or philanthropist. It is not funded by anybody. It grows by itself, grows itself and keeps growing. It's interesting that where there's a lack of resources, how social capital matters and counts, and how young people start volunteering their skills, their time, their resources to continue to ensure that this Fellowship continues to thrive regardless of lack of funding. Major setback of several fellowship would be lack of funding. But the GAiMF, through collaboration, creative ingenuity, volunteerism, social capital, and the love for humanity, has continued to thrive to support the wellbeing of the elderly across generations.

Linguistic and Cultural challenges

One of the major challenges we realized is cultural. Some of our Fellows are from the Middle East. They speak Arabic, some can't really speak English or communicate effectively. In recent times we have introduced the GAiMF mentor which focuses on the GAiMF for professionals and students in the Middle East, (Qatar) and North Africa (Tunisia and Egypt).

We also thought about using the GAiMF Infrastructure to create programmes that focus on French-speaking countries, on Latin America for those who speak Portuguese and for those who speak Spanish because language should never be a barrier to brain health.

So, we have to start thinking about how to make learning accessible, how to make learning in a way that people can understand, how to deliver interventions that are not not even delivered in English; and about how we start transcribing communications in a way that is easier for people to understand, to deliver interventions, to bring about positive change in their community.

Creativity and Collaboration through the GAiMF is bringing change to the lives of ageing populations in Africa, in America, in Europe, in Middle East, and around the world. Thank you so much, everyone.

Global Arts in Medicine Fellowship

Application reopens in January 2024.

VFG Chair Wow, Kunle, you're such an inspiration. We may think about making our Conversation transcriptions available in various languages.

CHAT

Furrah Syed FRSA Great work you are doing Kunle! Inspiration to us all.

Sarah Lasenby Thank you for telling us about these significant ideas about creative arts and how this can give us all hope.. I look forward to hearing more develpoments in future.

VFG Chair Our final speaker is **Dr Bogdan Chiva Giurca.** Bogdan is Development Lead at the Global Social Prescribing Alliance and founder of the Social Prescribing Student Champion Scheme. To mark Social Prescribing Day, he will co-chair a special Greengross Conversation in March between a range of medical and neuroscience champions on the impact involvement with participants at arts workshops for brain health is having for them. Here, as his mother has an urgent medical appointment, he has kindly recorded a video giving us insight into the scheme. Amisha Palmer, our Greengross Conversation Coordinator will run the video, thank you so much, Amisha.

Dr Bogdan Chiva Giurca, Development Lead, Global Social Prescribing Alliance – Founder GSP Student Champion Scheme

It's a true honour and I'm delighted to pay tribute to a great leader, Baroness Greengross, who's brought us all together to discuss regarding a subject very close to my heart, both as a human being and also as a medical doctor myself. I have three points that I'd like to share with you that hope stir the conversation into the direction of travel

- We are talking about more social prescribing accessibility from a clinical perspective.
- I also want to touch upon the idea of developing champions early on for the subject and the importance of education from an early stage in training and career pathways.
- And I'm going to end with talking a bit about the global perspective in social prescribing.

Social Prescribing Accessibility from a clinical perspective – a cultural shift

But without further ado, my first point with regard to social prescribing: what about art and culture that's always been around us for a long, long time? Well, social prescribing for the first time puts these interventions on the table for clinicians such as myself to use not after the diagnosis has been made – to support clinicians to go beyond pills and procedures and use such interventions as arts to prevent conditions from happening, but also to ensure and maintain brain health over a long period of time. It's a cultural shift and a paradigm shift that signifies the idea that for once we are looking at creating health within the community and at home.

Benefits of social prescription beyond bio-medical sphere

Sure, the arts have been around a long time; and the concept of social prescribing isn't new. But what's new is that I myself, as a clinician – for the first time ever – I'm able to build the trust necessary with individuals who are referred to the social prescribing link worker (SPLW) who's then able to co-design and co-create a pathway for them to get involved in the local community and their local environments at home, especially for those individuals who may not seek help in the first place. I'm talking about people who are lonely or social isolated, who would never seek our support in the first place and who would end up in my clinics and seek support from medical issues. Yes, they may come in with a heart problem or lung problems and we will give them the necessary medication. But such individuals quite often have problems that go beyond the biomedical sphere. In such circumstances, interventions such as social prescribing that allows us to refer people to local community services and have some handholding provided by the SPLW that provides motivational interviewing and co designs the treatment plan within, is very necessary.

Social Prescribing Champion Scheme

Social
Prescribing
Champion Scheme

Now, to my second point with regard to training and education, which I know will be a point that will be discussed in a future Conversation as part of this Greengross series. As a young physician myself, I believe education is at the core of how we guide our future doctors. We need to catch medical students. We need to catch university students and health professionals whilst they're young.

We need to support them and educate them while their brain is most malleable and open to change. Because what we've been doing for the past years, in the past decade or so, is we've been teaching people how to prescribe pills, we've been teaching people algorithmic pathways. But when we encounter social determinants of health, our algorithms fail. When the problem is related to how we eat, how we sleep, our finances, how much money we have, or the place we've been born in, our algorithms, our medical algorithms fail us. In these situations, having interventions such as social prescribing is crucial into the toolkit of the doctors of tomorrow. This is why, personally, I've been a big advocate for social prescribing being taught to students, not only medical students, but midwives, nurses, pharmacists, speech and language therapists at universities across England. I'm proud to say that over the past eight or so years, we've been able to integrate social prescribing successfully at medical schools and other universities across England through the Social Prescribing Champion programme, which you'll hear more about next time.

Global Social Prescribing

My final, final point is to shed some light on the practices happening across the world. Because social prescribing is certainly not a new idea. It's something that's packaged in a new idea, but has at the root and at its core, good community, integrated care that happens not only within England, but happens across the world.

I've travelled recently to Japan, where I've had the pleasure of seeing

- *Sheikat sotian*, Japanese SPLW, delivering social prescribing in the local community.

We've also seen:

- Asha workers in India, which is the equivalent of a health visitor that goes from house to house.
- Community connectors across Canada and other countries.

Regardless of how those individuals are termed, this new role and this new involvement in community-based care, be it through a SPLW in England, or through the social worker in another country, it allows us to tap into the existing assets that are present in the local community.

Need for investment in voluntary sector arts provision

But, as I've seen around the world, and certainly in England too, we need to ensure investment and support are given to the local and voluntary sector to deliver such activities. We know the research behind health and creative health and the research between arts and the connection between arts and culture and health is very strong. So therefore, it's time for us to start looking at how we can support the delivery of such activities within the local community and how we empower communities, not just use communities to provide those services.

Move towards preventative model for creative health lifelong

Certainly, for me as a clinician, this is a breath of fresh air. It's a move towards a more preventative model, a model where we create health in the local community before issues start to appear. And it's certainly the case for ensuring and maintaining brain health over the course of our lifetime, not only for the elderly, but starting with a younger generation and promoting intergenerational activities along the way.

I do hope to see you all soon, and I do hope this will lead to a further conversation today and I look forward to meeting you at our future Conversations.

Once again, we're grateful to Baroness Greengross for all the work that she's delivered in this field. She has been a true inspiration and will continue be an inspireation for young people like myself. Thank you very much.

Khan and Giurca et al, 2023 *Social Prescribing Around the World: A world map of global developments in social prescribing across different health systems.* ©National Academy for Social Prescribing.

VFG, Chair Thank you very much to Bogdan, who is himself a true inspiration.

CHAT

Jonathan Kaye Health policies seem to often result in clinicians ticking boxes and achieving targets at the expense of what matters to the patient. How can we change the narrative at the policy making stage? How can we deliver the evidence to policy and curriculum makers? Ticking the boxes and achieving such targets are currently obstructing other beneficial work at society and patient level.

Maddalena Illario Bottlenecks start early during the training of health professionals where there is only space for traditional learning. Maybe conjugating innovative approaches with arts could help produce more evidences on the impact? **Kunle Adewale** 'with ❤️' Well said Maddalena, we have medical students and educators becoming part of the global arts in medicine fellowship. Today, they are partnering with creative artists to bring in intervention into healthcare facilities in Nigeria

Maritza Pintado Caipa Hi, excellent session… I am a neurologist, and I think we need to change the way how physicians are been educated, many times separated of the art… to much to do Congrats! **Maddalena Illario** 👏 **Maritza Pintado Caipa** 👏

PANEL DISCUSSION - Collaboration

Now we come to the conversation between speakers and obviously the thread that runs through our discussions today, all these educational projects, is collaboration between the arts and sciences. It is extraordinary to think about the origami in Nigeria, bringing together young with the old and then setting up health society. It's the legacy of the programs that the training achieve is just simply wonderful for a better world. So let's talk about the challenges, the challenges that in fact, Kunle raised with regard to language. So, Brian, do you ever come across this? Because I know that some of your Fellows from far distant countries. And one of them in particular, I think she mentioned in Peru the language issue. The glory of art, of course, and creativity and culture and craftsmanship is in a way, that's one way of surmounting language. But I wondered if language has cropped up much in GBHI.

Challenge of language differences between medicine, science and arts

Brian, GBHI I would use the word language in a slightly different way. Kunle talked about the actual differences in language across countries, but I think there is a difference in the use of language and communication between science, medicine and arts. This is part of the siloing.

I found that as we tried to build and integrate arts and arts method into our Atlantic Fellows for Equity and Brain Health programme, I realized that there was a sense of a lack of equity and partnership between the artists clinicians and the scientists. And I think the artists often felt that people didn't really understand their methods and how they went about things; and likewise, the scientists said. ‘Well, the artists don't really understand where they're coming from either’. There is a difference in language and approach. I think that the artist need and the creative needs to understand the scientists and where the clinicians are coming from because these are different worlds and vice versa. We found that this takes some time and some work in terms of people appreciating the strengths on either side so that they can really work collaboratively together.

Clinicians’ lack of awareness of social prescribing and the benefits of arts for dementia

I'm struck by what Bogdan was talking about in terms of social prescribing. But I do think there is a lack of awareness sometimes among clinicians around the benefits of arts and arts for brain health and arts for dementia. I do feel sometimes that people who are providing those wonderful interventions, from the arts and creative point of view, are still a little bit distanced and siloed from the clinicians.

Benefits social prescribing champion scheme – early education in arts for health

I really love to hear what Bogdan is trying to do now with this Champions programme. It's trying to get in early with medical students, with healthcare professionals, helping them to understand the importance of the process, the method, the approach and the intervention early on, not just for their patients and for the people that they look after, but also for themselves.

How awareness of arts prescription can help heal clinicians and improve quality of care

I really, really believe that Arts creativity is not just a huge benefit for people with illness, but also for the clinicians. It can help heal the clinicians and decrease burnout and improve the quality of care that they can deliver and as I say, is good for their own brain health.

There is a communication issue, there's a gap. It's a language, but it's the language of science and the language of art, of arts and creativity. I think we need to pull those together and help people understand and appreciate so that they can communicate and collaborate more from a point of view of this equity and partnership. That's what I really want to see as we go forward. And I think that that's taken us about five or six years to try and build at GBHI. I think we're getting there, but we're not quite there yet.

VFG, Chair It's phenomenal, I must admit. I'd always invited arts student involvement at our arts workshops to re-energise and inspire dementia, then hearing Bogdan launch his Champions scheme, we invited neuroscience and medical students to join in with participants and help with evaluation – both for their educational benefit and for the arts organisation. I've also come across sometimes the arts being used for diagnosis. Is that much happening.

Brian, GBHI I guess, sometimes for people who've experienced trauma, arts can be used to help people express their emotions. With trauma, the left side of their brain, the language area, can be inhibited to some extent. So, in these circumstances, art and other forms of creative practice can help people express their emotions and can be useful in helping them work through the trauma.

VFG, Chair So at GBHI, when do the scientists and the artists students come together? How do they come together?

Brian, GBHI They're all together and they train together. Kunle can speak to this, but I think we're a little bit further on now than we were when Kunle started. We have a better appreciation of how to do it, and there's more equity in terms of that partnership between the artists and the scientist and clinicians. But they are together, they are learning, they're training, they're working together, and we encourage them to collaborate and develop collaborative projects together. It's not that straightforward because of the differing perspectives and as I said, it's about understanding that and giving them the space for them to understand each other's perspective and where they're coming from. Because the only way that we can build true collaboration for brain health and dementia is when the artists and the clinicians and the scientists are working in equal partnership together.

VFG, Chair How Fascinating.

Thomas, you too have the interdisciplinary approach. How do you bring in the scientists? All have a first degree, in arts, medicine, social science, who come to take the MASc, and artists who come, to learn how to use their art for health. How does it work at UCL?

Thomas, UCL I completely concur with Brian's point on the languages, because if you're talking about English, Spanish, French, Italian and Swahili There's Google Translate, there's translators that can communicate comfortably and we can translate things, but there isn't Google Translate to translate medical jargon into artist's jargon or artist's jargon into medical jargon. So I think that's a much greater challenge. The medics from all over the world meet happily at congresses and communicate. Artists from all over the world, to some degree, can communicate. The problem is really between those two silos.

That was, in a way, one of the key inspirations for us setting up the programme – to create a space where we can try and break out of those silos and have our graduates hopefully happily navigating these different worlds, and be equally comfortable with communicating with a group of clinicians as they are with communicating with a group of creative practitioners as they are communicating in a local community setting in East London, Bangladesh, or anything else. That was really the key. Obviously, that's a tall order, but it's reflected to some degree in the demographic and that's helping.

<u>MASc student demographic</u>

We do have students every year from a medical background. We have intercalating medical students, occupational, speech and language therapists, people who have been working in the NHS, in the health services for a number of years. Similarly, we have people who come from a fine arts background, who have been practicing artists, performing artists, actors, and we have people who have taken anthropology or epidemiology degrees. That's the key of the programme, that hopefully at the end, through this mix and the peer learning, as well as the programme that we've put together, they are then happy to communicate across the board on the benefits of arts and health.

<u>Language of evidence</u>

One key element that I think needs to be added to that question of language - it relates to the point that Brian was making – that there is still a lack of understanding among many medical practitioners, of the benefits of some of this work on arts, creativity, nature and health. It also relates to the language of evidence and the type of evidence that's accepted by the medical establishment. It is almost impossible for us on the creative side to match randomized control trials. There are certain things you can create randomized control trials on, but others you just can't. So that's another issue, another elephant in the room that we need to talk about.

(**VFG, Chair** We are planning, hoping to work together on a Longitudinal Study with UCL East)

Kunle, Arts in Medicine.

You said it so well. And I was listening to what Dr. Brian was saying and I think you being able to echo it was very good. The language between the science and the arts, which is sometimes very difficult. When we started the GAiM programme in Nigeria, we were not given access to work in the hospital because of lack of understanding of what the arts can do for health and wellbeing. But looking at what Thomas said, which I actually noted down about the language of evidence, I think with stories of impact, of how the arts really help being shared.

I think it's now encouraging access for carers and for medical practitioners to start embracing creativity. Because you cannot argue against evidence, show us if it has worked. Again, by telling the stories like some of the things Dr. Brian said about the change, about the programme development, all these are catalysts for access, for engagement.

<u>Clinicians witnessing impact of GAiM – as evidence - become Fellows themselves – enabling arts access for their patients</u>

One thing I will say regarding GAiM is that some of the medical practitioners, seeing the changes in the lives of the population they work with, then started joining the Fellowship. So what we now do is using insiders to gain more access, to deliver more arts interventions. Because again, at first it was difficult to penetrate, but now, by inviting insiders into the programme, we have seen the evidence. Now they become the crusaders and the evangelists of arts in health programming. Because again, it's easier for a doctor to convince another doctor that artworks than for an artist trying to convince a doctor that artworks the language. You get what I'm saying? It's easier, right? So bring in the doctors, bring the scientists, bring in the researchers. Once they're able to see the evidence, they become the crusaders again. They become the televangelists on the use of arts for health and wellbeing. And that is what we've seen in our programme. And that is why our programme has continued to grow. We've seen medical directors of established Government institutions in Nigeria becoming Fellows in our program, which has never happened before. Medical doctors.

Again, there's a power dynamics that comes with engagement. There's a power tozu that come with saying, oh, I'm in the science, you are in the arts. We don't have anything to do together. But when people start seeing positive change and how the union of the art and science benefits everyone, helps humanity, then I think that language is not undecipherable and access become easier.

Thank you very much, Kunle, Brilliant. Brian

Brian, GBHI Just maybe to round up on this, I agree completely with what Kunle is saying, but I think one of the difficulties we face now is actually who's in the room? I think the artists, scientists clinicians are in the room, but the actual managers and the commissioners are not necessarily in the room. And they're not in the room today, perhaps, and they need to be in the room. It speaks to the question that Jonathan Kay asked, how do we convince people? And I often found that the difficulties I think the commissioners have and the managers have is that they're dealing with people downstream. They're drowning, they're very ill, and they have to prioritize care, and they prioritize what's available and also based on evidence, so they don't prioritize arts and culture for health. We do need to get these people into the room.

VFG, Chair Brian, thank you and I am delighted to notice that we do actually have some NHS managers and commissioners on the call. (V adds It is always great to see and hear Dr Jonathan Kaye, who is clinical lead for dementia at Manchester Health and Care Commissioning and their Dementia Strategy Group; and arts and health teams get together very much at the Social Prescribing conferences, at the Cultural Health and Wellbeing conferences – Commissioners are key and many thanks to Jonathan!).

Michael Blakstad I just wanted to say that I'm on the way out in the sense that I've had a six-eighteen-month prognosis. So I am looking for someone who will take over my work. Might there be somebody be interested. Shall I describe what I do?

Media vs Dementia

I talked before about how media – I don't mean just television. I mean how new media can stimulate the brain when applied together. I've since had an intervention by a Southampton scientist Roxana Carare who says that clinically, this is a much better way of halting dementia than any of the pharmaceutical interventions which will not work because of the nature of the amyloids in the blood vessels to the brain. We are now on the verge of launching our campaign just to the point at which I'm going to have to leave it, which is a bore.

So I'm looking for someone who might take over. If there's anybody who's looking for a cause, please contact me (We haven't got money yet, but we will get some.)

** Media vs Dementia Seminar 2023, Friday 20th October, The Arc, Winchester 20th October ** - Come to that!

VFG, Chair Thank you and thank you all for coming today. Warm thanks to all our speakers for sharing your inspirational educational programmes you offer to bring social change through arts for brain health training and Fellowships – providing the ideal springboard for our Greengross A4D Global Arts for Brain Health Conversations. Warm thanks to Kay, Chris, Brian, Thomas and Kunle, it's been a privilege to host and hear you. And thank you Amisha for your superb hosting, marketing and technological assistance.

In our ongoing conversations the people who ultimately benefit from you will be the predominant speakers ongoing, plus their own specialist academic to set the context.

We look forward to welcoming you to our next Greengross A4D Arts for Brain Health Changemakers – Young Onset – Conversation on the 26 October

CHAT

Pernille Charrington Dear Veronica. Thank you so much.So very interesting. Best Wishes Pernille

Edward Chaney Great stuff... Many thanx all.

Maddalena Illario Thank you Veronica! Thank you to all experts

Furrah Syed FRSA Thanks Veronica for a great event. Appreciate all the inspirational talks.

Edith Wolf Perez Thank you for a wonderful inauguration. Looking forward to the next talks!

Katy Geertsen ❤️ Thank you everyone! 👍 **Linda Toigo** THANK YOU!

Kunle Adewale Thanks so much for the opportunity to share Love and light always

Lullyn Tavares Thank you Veronica and everyone. Lot of info to follow up on.

CONVERSATION **2**

Young Onset Conversation: Thursday 26 October 2023

Young Dementia Network

VERONICARTS
Arts for Brain Health

AGE
IRRELEVANCE

Arts 4 dementia
Empowerment through artistic stimulation

Greengross 'Young Onset' Conversation (Thursday 26 October 2023)

There are 3.9 million people worldwide - 70,000 in the UK – living with young-onset dementia (YOD, under the age of 65). Diagnosis takes on average 4.4 years to achieve, rather than two years for older people, causing greater challenge to those in employment with significant financial commitments such as a mortgage and they may also have families to support. There being at present no known cure, creativity is proving unexpectedly engaging for them, preserving cognitive function and wondrous sense of achievement, identity and wellbeing in the community, at our inspirational speakers will reveal in lively Conversation, chaired by Professor Jan Oyebode. Professor of Dementia Care, University of Bradford. The Angela Project (Improving Diagnosis and Post-diagnostic Support for YOD).

CHAIR

40	**Jan Oyebode**, Professor of Dementia Care, the University of Bradford.

PANEL

42	**Kate Swaffer**, author, activist, academic, poet, photographer, Australia
45	**Keith Oliver**, Alzheimer's Society ambassador, author, photographer, poet
47	**Wendy Mitchell**, author, photographer, social media champion, blogger
49	**Chris Norris**, tenor horn player in brass bands in Kent
52	**Gail Gregory**, artist and blogger
54	**PANEL Conversation**
56	**ACCESS & SUPPORT**
57	**Hamaad Khan,** Global Social Prescribing student champion scheme, SP as Access link between person, GP and arts programme
61	**Tessa Gutteridge**, Chair, Young Dementia Network. Programme Director for YOD, Dementia UK..
64	**Professor Adam Ockelford,** Professor of Music, University of Roehampton, 'The potential role of music to enhance the lives of children and young people with Neuronal Ceroid Lipofuscinosis (Batten disease).'

Greengross A4D Global Arts for Brain Health Changemakers Conversation 2

Veronica Franklin Gould, President, Arts 4 Dementia

Good morning and welcome to our speakers and delegates from around the UK – many from the NHS, which is good news! – from Australia, Austria, Ireland, Italy, New Zealand, Nigeria, Singapore, Taiwan, and from the United States of America.

Today's Greengross Arts for Brain Health – Changemakers - Young Onset Conversation will bring insights from inspirational people who since their diagnosis with a YOD have been living remarkable lives through creativity – for most, as never before. And Chris, having given up playing his tenor horn after heart attacks, when dementia struck he thought blow it – or rather, I'll blow the horn again – and a decade later he is still at it!

Our chair, Professor Jan Oyebode, a specialist in the field and Head of dementia care at the University of Bradford, will lead today's Conversation. We are honoured to be able to hear and share how, despite the challenges of dementia, Kate Swaffer of Australia, Keith Oliver, Wendy Mitchell, Chris Norris and Gail Gregory, advise, write, create poetry, photography, art and music - to live their best possible lives. In a fascinating Panel Conversation, they will exchange experiences of their creativity and its impact.

Then we look at Access: Hamaad Khan, Global Development Officer at the National Academy for Social Prescribing, explains how social prescribing provides the link between the patient, through the GP surgery, to arts and wellbeing programmes that can empower them to preserve their brain health. Hamaad will touch on global social prescribing approaches, and the champion scheme that encourages medical and neuroscience students to interact with these artists, to glean insight into their condition and material for dissertations.

Tessa Gutteridge is the driving force behind Young Dementia UK and Director of the Young Dementia Network.

Each person will talk for about five minutes and the resulting Conversation between them will open our eyes to the reality and impact of arts to preserve brain health in Young Onset.

Finally, in view of a tragic need, Professor Adam Ockleford, a specialist in music for children facing exceptional challenges, will explain how this helps children with Batten Disease, a symptom of which is dementia.

The instigator of this Changemaker Conversation series, Baroness Greengross, was passionate about the need for music to be embedded in the health and social care system for dementia. Sally, our dear friend, Arts 4 Dementia patron and Co-Chair of the All-Party Parliamentary Group on Dementia, worked indefatigably to advance arts for brain health strategy in Parliament. And after her death last year, many of us learned that she and her husband created the British Museum's Youth programme– how Sally would have valued our focus today on Young Onset!

We are truly grateful to our speakers whose guidance inspires best practice in arts for brain health the world over, to Nigel Franklin of A4D for technological wizardry and to uur colleague Amisha who will keep an eye on and preserve the Chat and help edit the recording for an online resource, together with this transcript. If you would like to upload your own resources, we shall add those too.

I should like to introduce our chair. Jan Oyebode, Professor of Dementia Care at Bradford, has spent most of her career as a clinical psychologist in the NHS. She now works in research, where her current focus is on relationships, coping with life with dementia, and family caring. Her recent work includes The Angela Project – improving diagnosis and post-diagnostic support for people with young onset and their supporters; The DYNAMIC project – on social care for people living with YOD and their families. She also leads the Young Dementia Network's research workstream.

Jan, it is an honour to welcome you as chair:

Jan Oyebode, Professor of Dementia Care at the Centre for Applied Dementia Studies, University of Bradford.

It's a real honour for me to be here. I think we're all going to have such an enriching time, getting this conversation together, with several people who are very inspiring figures in the young dementia world and the dementia world generally, and who are outspoken advocates for good support and services for people with dementia.

I think it's wonderful to have a focus today on Young Onset Dementia (YOD). It's catching more attention now than it used to. That is largely thanks to prominent voices who've been acting to draw attention to the needs of everyone with dementia, but especially for people with YOD because, as you see from our panel, these are people who are younger themselves. First of all, Veronica invited me to speak briefly about The Angela Project.

The Angela Project (2016-19)

This was a project funded by the Alzheimer's Society in the UK to run from 2016 -19. We are still producing outputs and resources. The project aimed to improve assessment and diagnosis and post diagnostic support for people living with YOD. It was led by Janet Carter, who is an old age psychiatrist working in North-East London Foundation Trust and at University College London. She led the work on diagnosis, along with Professor Jackie Parkes from the University of Northampton. We ran the post diagnostic work stream from the University of Bradford. Keith was also involved as a key member of our Involvement group. We surveyed people living with YOD in the post diagnostic work stream to ask people about the services and support they received. We had responses from 233 people living with YOD or their family carers. They were a mixed group of people aged from their 30s to their 60s, with an average age in the 50s.

Survey headlines – only one in five able to access specialist service

Just drawing your attention to some headlines that came from this survey. Only 20% of people received any specialist service. The Specialist services for YOD were associated with higher satisfaction and higher quality. They provided better care continuity, and there was better care planning, but only one in five people were able to access a specialist service.

About half those who responded to the survey accessed some dementia-related activities, but just under half hadn't attended any dementia related activities in the three months prior to completing our survey.

Care costs

The cost of care is very modest for people living with YOD. People were using Health and Social Care and Third Sector Services, which cost on average £394 per three months. But for Family Care if you totted up a total based on the pay a care assistant, families contributed care worth over £8,000 in that same three-month period. So we can see that families provide a lot of support. Official services aren't providing a lot of support. We knew that there were difficulties in accessing services, and we wanted to find out more about what was really helpful. We asked people to give us a brief description of any service they'd found helpful; and we analyzed these to understand what they were, how they were provided to be helpful, and why they were helpful. Our 233 respondents sent in over 850 examples of positive services. I think this makes us feel more hopeful to know that there are a lot of things that people living with YOD do find helpful.

How Services Helped

We tried to distil the essence of these from all the examples. There were three reasons why services were found to be helpful. Firstly, they helped the person living with YOD to maintain independence and autonomy. Secondly, they enabled the person to be themselves, to have their own identity; and thirdly, they enabled people to feel connected with others and the world.

Creativity and the Arts – the power of music as self-expression

Now we didn't ask people specifically about arts and creative activities. And because we asked about services and support, a lot of people told us about conventional health and care services. But people did also mention creativity and the arts, and I just want to finish my brief few words by giving you an example from someone who spoke about the place of music in his life. He said, ‘Once you've got a diagnosis of dementia, most people define you by the diagnosis and not based upon your potential and who you really are. And that makes you reluctant to engage with anything.’ He said, ‘What's been good for me has been music and situations where people allow me to play that music and express myself. People recognize what I do is relevant. I'm still full of the person who I used to be, who I am. I'm still full of the youngness, full of the energy and full of the enthusiasm. What's important for me is something that's compatible with who I am.' He gives us an example of how music and creativity in his own life helps to contribute to him feeling that he is very much himself and valued as himself by the people around him.

In the transcript, you'll have links to the Young Dementia Network site – all the outputs from our project are there for anyone to access, with articles and other resources connected with The Angela Project.

Let's turn to our panel. Each person is going to have a few moments to say something about themselves and the part that creativity plays in their life.

THE CONVERSATION PANEL

Kate's such a well-known name I feel I'm in the presence of the royalty of the dementia care world here today. Kate is a researcher and a published author and poet, and a global campaigner for human rights and disability rights of older people and people living with dementia. We're delighted to have you with us today from Australia, Kate, and to hear about the place of the creative arts in your life.

Kate Swaffer, author, activist, academic, poet, photographer, Australia

Thank you so much, Jan, and welcome, everyone. I'll just start with a special thank you to Veronica for the invitation to be with you today and to join so many wonderful friends also living with dementia; and also thank you to everyone for making time to join all of us. I know some of you and know some of your names and your incredible work in dementia. So together, maybe one day we can change the world!

I thought rather than focus on my creativity, which I'll discuss very briefly, but I think that the reason that so many of us have turned to creativity is really what happened to me and what happened to many people before me, to people such as Christine Bryden and the late Dr. Richard Taylor and then has happened to so many people still.

My diagnosis 'guidance'

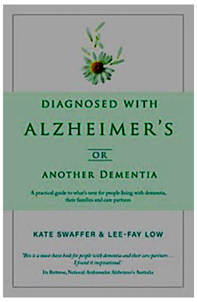
Being diagnosed with a rare YOD as a 49-year-old married working mother with two teenage sons was truly pretty traumatic. Particularly because I'd been a nurse and I didn't know that young people could get dementia. But what was worse than the diagnosis, I felt, was that being told the only thing that I could do was to go home and prepare for the end. Get my end-of-life affairs in order and there's nothing we can do. So I think for me it was a spiralling downhill to start with. And for my husband and teenage kids, I thought that there was no hope for any sort of future together as a family. Thankfully, I had a couple of lucky breaks.

University response – Accommodating Acquired Disabilities

I was a mature age university student at the time. My lecturers were perplexed about why everybody else told me to give up everything – they just saw me as a person with acquired disabilities and referred me to the disability support Team. But my employment was terminated upon disclosure of the diagnosis. Although dementia causes disabilities, we all know that now and the World Health Organisation have been saying that for 15 years, in fact since before my diagnosis, not one healthcare professional or service provider has advised me ever until quite recently that I had rights under the Disability Discrimination Act in Australia and the CRPD to be supported to stay at work.

CHAT Veronica, A4D: In 2019 The All-Party Parliamentary Group on Dementia, co-chaired by Baroness Greengross and Debbie Abrahams MP launched the *Hidden No More: Dementia and Disability* report.

The other factor that impacts my more positive trajectory is that I soon realized and I'm a retired nurse also – there's some other retired nurses in the room. I believe. Wendy – I realized if I'd had a stroke, age 49, I'd have been offered rehabilitation and supported back to work with disability adjustments if needed. And the creativity part is really important. But we really have to question why the dementia and healthcare sector tells us to go home and prepare to die.

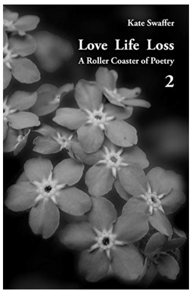


In my experience the education system supported me to keep living Kate Swaffer's life, as a person with acquired disabilities. I think being supported as a student enabled me to continue to live my own life, meaning I could continue with my studies and I still get support from a university today disability support.

No support from the Healthcare sector – Disability Rights issue

But I still don't get support from the healthcare sector. So it is a major rights issue facing people with dementia. I didn't want a new identity. I wanted support to maintain the one I had.

Dementia's gifts – new friends, maths replaced by creativity



That doesn't mean that having dementia has been all bad. Dementia has given me many gifts, and it's introduced me to loads of amazing people around the world, like many people on this webinar. It's given me a clarity about life and about people that I didn't have before, despite the increasing fog. And I wasn't a poet before dementia. I wasn't really interested in photography and design. And all of those things have taken over the parts of my brain that don't function like they used to, like my photographic memory, my high level of maths ability that's gone. I can't even use a calculator anymore. But these other creative gifts seem to have turned up to replace the things that have gone missing.

New Creative Thinking and Skills – Pictorial Vision

So, whilst there are progressive changes to my cognitive capacity and my memory and thinking, my memories change, my thinking. I see things in pictures now, which I believe is very much like people with autism. And I actually believe through continuing to study and to continue to be so active, as many other people here with dementia are living active lives. I think we are creating new neural pathways in our brain.

Focussed Rehabilitation – Need to Support and Encourage People to Live Well

The other thing because I had been a nurse and was able to fund it, was a really focused rehabilitation programme similar to someone post stroke. We need to support people to live their best life possible with dementia, not only to prescribe, giving up and preparing to die from it. And yet most of the people I meet newly diagnosed through Dementia Alliance International are still advised to prepare for the end, and there's nothing that they can do to live a positive life.

People who don't believe we have dementia

There's a couple of things I just wanted to say about – and some of us here have faced this challenge – living more positively than an expected with dementia, particularly living more positively than people who are older and in a later stage of dementia. There's been a group of people around the world who quite publicly say they don't believe we have dementia. My own neurologist was quite insulted by that, is as if there's a group of people who don't believe he has the capacity to diagnose a person with dementia, even though that's half of his patient cohort.

Creative Gifts that Keep Giving – Poetry, Photography, Music, Gardening

But for me, the gifts that just keep giving are the poetry and photography, which I didn't have an eye for photography. A much stronger interest in gardening and a really changed and very different musical palette now. They've been incredible gifts of dementia. And I do think that the other really important gift is it puts everything in perspective. And you really do learn to just enjoy whatever you get today and not worry too much about what might happen tomorrow.

CHAT Kate Swaffer, Kaurna Country Here are links to my books *What the Hell Happened to my Brain: Living beyond dementia* and my poetry books –

J.O., chair Thank you. That was just such a rich five minutes. You've said so many things that I'm sure will strike a chord with lots of people listening; and you've packed so much in there in terms of words about our rights and the importance of hope, but also the opportunities to live our best life possible; and the gifts that you didn't expect that dementia has brought you. Thank you so much. We will hear more from you in a little while and let's now turn to Keith.

J.O., Chair Keith Oliver is a retired head teacher and we've known each other for a lot of years now. And Keith has written short stories, books, poems and now has started to produce watercolour paintings and artwork. He is going to tell us a little about his life and how it's going and the connections with creativity.

Keith Oliver, Alzheimer's Society Ambassador, human rights activist, author, 'Photography, Painting and Poetry'

It is wonderful to be here this morning and a real privilege to follow on and take the bat on from my dear friend Kate. Moving on then as part of maintaining my wellbeing, it is now not overstating the fact that creativity and stimulating leisure activities makes life for me worth living and has filled so many vacuums in my life which have been created by Alzheimer's.

Intergenerational collaboration

There are a number of threads through my talk, the value, first of all, of intergenerational collaboration in the arts, pursuing activities as an individual for my own satisfaction or in a group when sharing the learning and the results, which often includes encouraging and supporting one's peers. I've subtitled my little contribution today as the three Ps, 'Photography, painting, and poetry'. And we'll explain why as I go along.

Photography

Firstly, photography is the only creative pursuit amongst the three which I have enjoyed and practiced since well before my dementia diagnosis, which occurred on New Year's Eve 2010. I taught creative black and white photography as part of my art curriculum to primary school children; and then in liaison with a local secondary school, taught the children how to develop and print their images in a dark room. This was an exciting and adventurous activity for us all in more ways than was always anticipated with children collaborating and creating together in a dark environment.

Then since being diagnosed. I have become the photographic student – learning with others who have dementia how to make better use of cameras on my iPad and smartphone. This has been through two dementia projects here in Canterbury, one funded by the Arts Council and the Dementia Engagement and Empowerment Project (DEEP); and one by Kent County Council, the latter combining photography with poetry and music to enable people with dementia to express a creative narrative of their own.

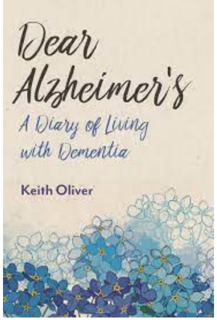
Painting

Between the ages of eleven and 64, my sole use of a paintbrush was to paint walls and ceilings with my wife in our home. After Lockdown, I joined an online art group led by Frances Isaacs and my dear friend Gail was part of that group as well. I was introduced to a skill and a passion which I never knew I had, which is watercolour painting. This has completely changed the way I look at the world in which I live. I don't copy when painting, but try to take a story in my head and transfer it onto paper using paint. This has encouraged me to be more resilient, patient to rework ideas and take risks and some happy accidents have been the result.

Similarly, it is only since being diagnosed that I have written poetry, some of which I have been very fortunate to publish. I'm going to finish mine a little bit with a poem, which I wrote some months ago and which seeks to turn stigma a negative stereotypes on their head and was recently the subject of an Arts Council funded film. Depend upon which where you put the emphasis on the words. Is called atrophy.

A - trophy

Re-reading the neurologists report
Nearly said my neurologist
But he doesn't belong to me
And I certainly don't belong to him
About a brain which does belong to me
Why does the word atrophy jump out
Puzzle me, concern me, cause me to self doubt
Surely atrophy should be reason to celebrate.
Who has given me atrophy
Shook my hand in exchange for a smile?
This is atrophy shared with family and friends
Whether they like it or not.
Picturing atrophy in my mind
Filling in the gaps
Atrophy maybe for my brain
For sporting achievement
For effort, for trying (very!)
For quizzing – a good memory test
Even for being ME.
I don't need atrophy to remind me
How hard it is to remember
But what some people say and do shines through
A trophy that many compete for
Are given
But few will want to win
Maybe around the base
We have names engraved
Past winners, past friends, past ...
In atrophy so we never forget them.
Fair to say sometimes
It feels my brain is shrinking
But then my heart gets bigger
Maybe that's what deserves atrophy!



J.O., Chair Thank you so much, Keith. That's such a beautiful poem, and beautifully delivered too, really lovely and you have achieved all this living with a brain that has some cognitive problems, but demonstrating to us just the sheer creativity that has arisen since that diagnosis, I think, is so inspiring.

CHAT bisakha sarker Beautiful poem **Keith** Poetry by Writers with Dementia What a great webinar.

J.O., Chair Next on our starcast is Wendy Mitchell. Lovely to see you, Wendy. Wendy has lived with dementia since I think 2014 and has a blog Which me am I today? where we can all read about the day to day adventures, trundles and visits to paradise, as well as other things. Wendy is also author of best-selling books, which if you haven't read them, I do highly recommend. Reading Wendy's books if you are working with people with dementia, you would learn so much. Wendy, over to you.

Wendy Mitchell, author, photographer, social media champion, blogger

Thank you. And as Keith said, it's so lovely to share the stage, if only online, with so many wonderful friends.

Throughout my life, I've had many artistic interests, but dementia has taught me the importance of Time – and how!

Time – Enjoy the moment!

This very moment is the only time any of us are guaranteed, as no one knows what's around the corner. I was as guilty of anyone in my working life of wishing for the weekend, wishing for the following day, wishing for the next holiday. But now I simply do my best to enjoy today. Enjoy this moment. Nature has taught me to enjoy the smallest moments during lockdown which everyone found difficult. I realized I needed to find a new routine.

Photographing Nature – Take Time to Stop and Look, Really Look!

As my old routine of traveling three or four times a week around the country, giving talks disappeared, by pure chance I bought a camera just before lockdown. One day I saw it staring at me from the bedroom carpet. Could this be the answer? Because I never had time to discover my village before – I was too busy traveling. But how the world had slowed down.

The Camera Lady – seeing dementia in a new light

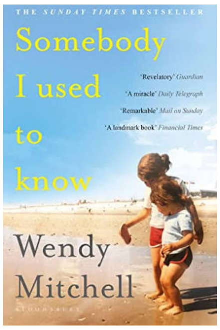
I went out each day taking photos along the way. Clicking those magical moments so often missed if you don't take time to stop and look. really look. I discovered we had a village Facebook page. So each teatime I'd post my photos and the comments that came back were so wonderful, so heartening. We were having to stay indoors. So it's lovely to see village life through photos. Another said, I never realized our village was so beautiful. You see things we all miss. This different means of socializing with the community around us is what got me through this strange period we all faced. Most villagers didn't know I had dementia at the time either.

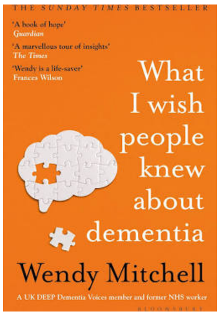
CHAT Berni God Wendy you inspire me with your camera ! ❤️

Word began to get around that I did have dementia. But instead of calling me Wendy With Dementia, they started calling me 'The Camera Lady'. They saw my talent with a camera before they saw my dementia. So now they saw dementia in a whole new light. I still post my photos every single day on the village Facebook page and the villagers even asked me to produce the village calendar for two years to raise funds for the village but also my support group. So my new hobby helped me as well as many others.

Which Me am I Today?

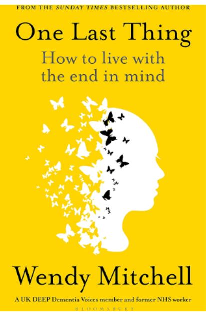
My other main therapeutic passion is writing. I can type words faster than I can think and speak them because that part of my brain hasn't luckily been affected yet. Typing is my escape from dementia. My blog *Which Me Am I Today?* is simply my memory. But it's so humbling to think that people all over the world read it. It was the blog that led to publishers asking me to write my first book. But I kept turning them down. I knew I couldn't write a book by myself because I'd never remember what was on each page as soon as I turned it over.





So when the lovely Anna Wharton, emailed me out of the blue and said 'I think we could write a book together' that I'd wished I'd had when my father was alive. Suddenly, the impossible was becoming a possibility. I didn't want Anna to write my book. After all, she's a ghost writer. I didn't want her to just interview me and write my book. It wouldn't be my book. So we found a way whereby it worked for both of us. She told me what we were writing about each day. I typed my words. Then Anna would work her magic and weave it into the storyline and keep it all in time order. That's how we wrote my first book, *Somebody I Used to know* and my second *What I wish people knew about dementia*. My publishers are Bloomsbury, the same publisher as Harry Potter. Where's the connection? you might ask. Well, I was diagnosed on Harry Potter's birthday, 31st July, so the partnership was simply meant to.

My last book



But Anna has taught me the art of writing, the importance of writing is the detail, just like the click of a camera, the detail that so often missed. That's why I know my last book. *One Last Thing* is my final book. As through writing that I discovered the balance was tipping in Anna's favour. And for me, a book isn't my book unless I've written it.

So they're my two creative pastimes. After all, we all had talents before a diagnosis of dementia. We don't suddenly lose those talents overnight when we're diagnosed and with help and patience we can learn new ones. Thank you.

J.O., Chair Thank you very much, Wendy. A lot of really interesting words of wisdom there. Your focus on time, the importance of time, and the time that the terrible pandemic gave you to observe and then allow your photography to flourish, that's really fascinating.

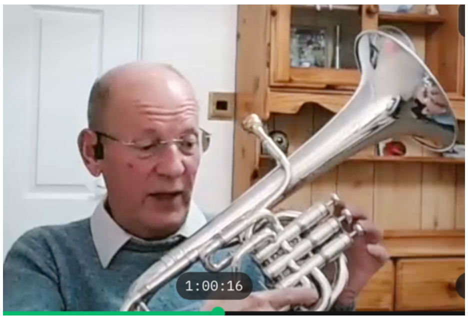
J.O., Chair Our next panel member is Chris Norris. Chris was diagnosed with frontotemporal dementia just over ten years ago now. We haven't really heard yet from someone who's a musician. But Chris blows the horn and is going to tell us a bit about the place of music in his life today. Over to you, Chris.

Chris Norris, tenor horn player in brass bands, Alzheimer's Society Ambassador, Kent Dementia Envoy

Thank you, Jan. And good morning, everybody. It's great to see everybody here. It occurred to me earlier on in the talks, people were saying that they see us as a person with dementia, and they don't see the person behind the dementia. It occurred to me when I looked at the picture of me blowing the horn and saw instead a picture of a light bulb in the ceiling – unfortunately, the rest of the picture of me actually playing my tenor horn had disappeared off the screen – it rang a bell with me. Well, there you go, that just goes to show – we're more than the dementia and I'm more than a light bulb.

Cornet player in the Mounted Band of the Lifeguards

So whizzing on, I started my music playing when I was eleven; and I went into the army at the age of 15 as a junior musician in the Mounted Band of the Lifeguards. I had to be able to play my instrument. My weapon of choice at the time was the cornet. I had to be able to play that riding on my horse, which is no mean feat, because of course horses have a mind of their own and they sometimes don't do what you want them to do. When I came out of the Mounted Band of the Lifeguards I joined the Kent Police. And about a year after I joined them, they started the Kent Police Band. So I was a founder a member of that and at the time. I decided to change my instrument.



I feel a bit like a ventriloquist now because I'm going down into my box of tricks, and there we are, that's what a tenor horn looks like. So a bit different to the cornet. Well, it's the same shape, but it's just, on its upright when you play it. So that's a tenor horn. And in brass bands, it replaces the French Horn that you see people playing in the orchestra, where they shove a hand up the bell and tootle. I played away nicely, then

Heart attacks stopped Chris playing the horn

Unfortunately, in 2008, over an 18-month period, I had three heart attacks. The consultant told me each time, Chris, 'You really should stop playing your music. You're putting too much pressure on your heart.' I didn't listen because music was a part of me and had been a part of me. But when I had my third heart attack, I thought, well. I just must listen to what I'm being told and give up playing. I stopped playing for five years.

FTD diagnosis, blow it! – Triumphant music for wellbeing

Then I got my diagnosis of frontal temperature dementia (FTD) and I thought, oh, well, blow it. As Jan said earlier on *Well, blow it*! If my heart doesn't get me, the brain's going to get me. So I went back to it. I'm happy to say I haven't had any heart attack since then. So there we are that's jolly dinkham.

A4D Music Reawakening

Then I was invited in 2015 by Veronica to take part in the Arts 4 Dementia programme for musicians with YOD; and this was joined together with the English Chamber Orchestra musicians and London College of Music students. And we all sat down and talked about the challenges that I had and that we found coping mechanisms and ways around the difficulties of doing things. I've lost a lot of things that I had learned when I was at the Royal Military School of Music at Kneller Hall in Twickenham. I'd forgotten those and I was losing some of my techniques. But between as we managed to find ways around it.

Transposition – mutual learning

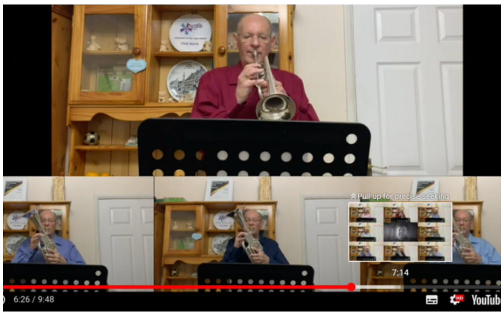
They also learned things because they never had to transpose their music. They just played what was on the page. Whereas if I'm playing along with them because my instrument is in a different key, then I have to be able to transpose which I've lost the ability to do. The upshot of that was, we then put on a performance at the Wigmore Hall in London, which is a very grand place, we composed some music; and we put on the performance there – which just proves that people living with dementia still can and still do.

Welcome to Our World

Welcome to Our World
A collection of life writing by people living with dementia
with foreword by Jo Brand

Along the way I also joined Keith Oliver. In writing a chapter in one of his books. *Welcome to our world*. I'd never done any life writing before. In those chapters we talked about life before, life with the diagnosis and what you saw into the future. So that was all very exciting. That's the only time I've gone into that side of things.

DEEP *I've Got You!*



Then on the 10th anniversary of DEEP, which Keith mentioned earlier on, they put together a video called *I've Got You,* and if you go onto the DEEP (Dementia Voices) website, you can see *I've Got You* and they got me to do all the music background. So in places in the film there are nine pictures of me on the screen playing all the different parts which I thought was quite interesting and funny. It's a bit like

Celebrity Squares, really. It was really quite funny. I put on a different shirt and jumper for each picture on the screen. So it looked like there were nine of me.

Learning a new instrument

During lockdown, the group that I belonged to decided that we would do our own research about music. We looked into the idea. Is it possible for people with dementia to learn a new skill and we found that it was – we all learned the ukulele. We managed to put on a performance – none of the others were musicians. They all thought I'd be able to do it easy-peasy-lemon-squeezy. It wasn't the case. Learning a new instrument can be challenging, but we were all chuffed with what came out at the end.

Worries floating away with horny fiddle

You have to laugh sometimes with dementia. Recently I was sitting on a Q&A panel on stage in front of an audience, around the arts. I thought the audience knew that I was a musician. But as I found out, they didn't know what context it was. They didn't know I played the tenor horn. I was asked a question as to how music helped me. I replied that when I get tired and frustrated, I take out my horn and have a jolly good play and fiddle with it, and all my cares and worries float away. I noticed that I was sending the audience into hysterics because they didn't know that I played the tenor horn.

Laughter the best trip on words

I find these days when I start talking, the words just keep coming out. I know something's going wrong, but I can't stop them anyway. Everybody was in hysterics. I had to explain to them. Yeah, I'm a tenor horn player. So when you're living with dementia, I've learned to laugh when dementia sticks out its foot and trips us up. I think that's what living with dementia is looking at the things we can still do and not the things that we can no longer do because there's zillions of things we can still do. Thanks very much.

CHAT Kate Swaffer Laughing is also my way to cope with the changes! it sure beats crying

J.O., Chair Thank you, Chris. That made me smile. Probably made everyone listening to you smile as well and that message of the things that you can still do and you do do carry you forward, despite that advice you had not to carry on playing. So thank you very much.

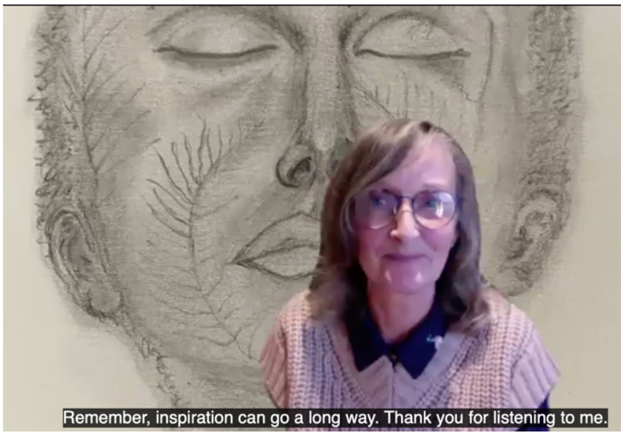
Last, but not least on our panel of people living with YOD today is Gail. Gail Gregory was diagnosed three or four years ago. She lives in Lancashire. Gail received a diagnosis three or four years ago. Now in her early 50s, Gail writes a blog and has a talent for art. And you can see an art piece behind Gail now on the screen. And she's going to tell us a little bit about the place of art in her life.

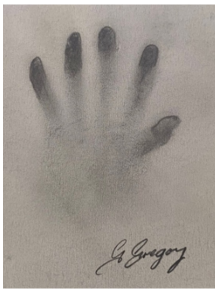
Gail Gregory, artist and blogger

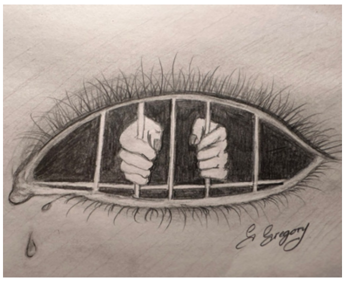
Thank you so much for inviting me to join you all this morning. It's an honour to share with you how I keep my brain active while hopefully I'm inspiring others.

Difficulty of diagnosis

When I received my diagnosis of early onset Alzheimer's four years ago, I felt empty. I felt lost. Not only had I received my diagnosis, but I had the very difficult decision to give up my business. The business that I had worked so hard to create, so I felt like I'd lost everything. I felt like I'd lost all purpose in life.







Culture, Creativity and Writing Restores Sense of Purpose

It was arts, crafts, photography and my blog that brought a sense of purpose back into my life. I needed to find ways. That I could keep my brain engaged. Our brains are very remarkable and require regular exercise to stay sharp and function at their best. So I needed to ensure that my brain was staying active. Now, for me it was arts and crafts, nature and photography.

Challenging Myself to Promote Brain Health

I do like to challenge myself with new information and skills. And I believe by doing this I'm hopefully promoting my brain health and holding on a little longer to my cognitive function. By incorporating my arts and crafts into my daily life, I am hoping that I will keep my brain engaged much longer.

I always like to start my day with an early morning walk and that's joined with my four-legged friend Toby, who was a celebrity in his own right and poses regularly for photographs that are shown on our local weather TV station.

Camera as Memory Aid

I love being outdoors just to soak up the beauty of nature and capture my walks on camera because it just doesn't take photos. It's a wonderful memory aid and I can relive my walks on my photographs later. The sights and sounds of nature are just so calming. And I have indeed countered some very special moments with nature. I'd even had little Robins feeding from the palm of my hand. Such a great way to start the day.

After a good dose of fresh air, it's off into my craft room. Or I sit at the computer and write up my blog, depending what inspired me on that particular day.

Inspiration can be very powerful. It has the ability to ignite others and encourage others. An inspiration can come from many, many different sources. Lots of things inspire me to be creative. Other people, flowers, nature. The list is endless. We all have so much beauty around us. If only we would take the time to stop, to look, and to listen.

Dementia Inspired Me to Try New Things

A supposed dementia has inspired me because it's given me the opportunity to try new things, to be creative and to use my imagination. I do try to attempt a piece of art.

Art to Calm Me

Most days it helps to calm me as I immerse myself in a piece of art. Dementia seems to disappear. I have no confusion. I have no agitation. It's just me and my artwork. Arts, crafts, nature, and photography is my form of mindfulness.

Learning Art Post-Diagnosis – Great Comfort in Mastering New Creative Skills

I had never done any drawings or any paintings until after my diagnosis. That was all thanks to a wonderful lady called Frances (Isaacs), also living with dementia, who encouraged me to try drawing in watercolour. I was so surprised when I found out that I could actually draw and I could paint. But the biggest thing was that I was learning something new whilst living with dementia. Art became a way of bringing out a creative side in me that I didn't even know existed. I started to express myself on how dementia made me feel. It was becoming a way to release the feelings and emotions that I was carrying inside. My blog and poetry helps also. It's just a great comfort to let things go. There are so many benefits to arts and crafts, nature and photography. I believe by doing these that I'm keeping my brain active and it's beneficial to my wellbeing.

Health Benefits of Artistic Achievement

It reduces my stress levels. It alleviates my symptoms of anxiety. It helps me with the feeling of loneliness. And it keeps my brain active. The best thing of all is the feeling of achievement when I've actually completed a piece of artwork.

Art Brings Power to Motivate, Inspire Others

So let us embrace the power we have to inspire. Encourage and motivate others. Let us be a trigger for change and make a positive impact in the lives of those around us. Remember, inspiration can go a long way. Thank you for listening to me.

J.O., Chair Gail, thank you very much. And very appropriate to end on a type of call to action for us all to show how, living with dementia or not, we can inspire others, and we can help others to see some of the ways that we can enrich our lives. I think you've all spoken about having very rich lives. Thank you very much Amisha for showing Gail's wonderful drawings. Thank you.

THE PANEL CONVERSATION

We have just a few moments for everyone on the panel to talk to each other. Welcome back, everyone. You've all said things that connect with each other. And I'm sure you'll have been listening to each other and thought, 'Oh, yes, that resonates with me'.

Chris

Let people know we have dementia

Yes. I think sometimes when you're living with dementia, sometimes people are a bit shy to let other people know that. Dementia does exist in their life and in my banding. I now make sure that people on either side of me know that I'm living with dementia and they are very helpful. They will subtly lean forward. If we're told to go from a certain place on a piece of music, they will lean forward and count on the music as if they need to know where they are. I know *they* don't need to know but they are just subtly helping me. If I didn't tell them, they wouldn't do that and I would not be able to carry on as successfully as I am. So I think it's very important that we let people know of our conditions.

Giving Inspiration to Others

What Gail said about inspiration to other people is bang on the nail because it puts things in a totally different context, that we still can. When you look at the things that the people on the screen have done, you think: Wow, we're no different to everybody else. We achieve things. And we will carry on achieving things. And there's no stopping us because we've got the power to go on. Thank you. Thank you, Chris. Smiling broadly.

J.O., Chair Wendy?

Wendy

Friendships

To me through all this is the friendships, how we've encouraged one another. We've all had that dreadful experience of diagnosis.

Hope

We've not heard that tiny four-letter word that means so much to anybody - Hope. And yet all of us. *Kate was the first person to give me hope*. It's that if we were a company wed be succession planning. To keep that motivation and that knowledge of can-do attitude. And I think that's just shone through today.

J.O. Chair Yes - and Kate?

Kate Thank you. I didn't know that, Wendy. It's lovely to hear that, thank you. And I started blogging, maybe 2009, I think that was, before the book.

Tell People You Have Dementia

But I wanted to comment on something that you said, Chris, because I think it's really important. You said that we should tell people that we've got dementia and not be fearful of doing that. I had a lovely example of a close nursing friend and her husband come to visit me one day, maybe three or four years into the diagnosis. And they sat down and asked me how I was. And I did the typical *I'm fine*. Probably everyone says that down the street because we all think nobody really wants to know what it's like. My friend's husband said, ‘Now, Kate, I'm sure things aren't fine all of the time. They might be right now while we're visiting. But really, if you don't tell us what it's like for you, how can we actually support you?’ And I really took that to heart, and there's been some negatives to taking that to heart.

With Cancer, Parkinson’s Disease or Diabetes, We Wouldn’t be Fearful or Ashamed

But seriously, if we had cancer or if we had Parkinson's disease or if we had diabetes we wouldn't be fearful or ashamed of telling other people if it came up in conversation.

Be Upfront – Break Down the Stigma

I think that one of the ways that we can help break down the stigma is to be as upfront about having dementia as we would be about cancer. A very high profile media woman in Australia – she's currently Chair of the ABC Television Channel was quoted a few years ago ‘when Someone Gets Cancer, everyone swarms around you, promises to be with you’. - I don't know if anyone has had cancer - everyone promises to be with you and hold your hand till your last breath. But when you tell them you got dementia, a significant proportion of those same people quietly disappear. Is it that they're scared? Or is it this late-stage dementia that they think we're going to go straight to? Is it that they're fearful for their own potential to have to. There's too much fear attached to dementia, so we can't be open. We just need to be open about it like we would about anything else.

CHAT

Kate White: My partner and I emerged from feeling shame to being “out and proud with Alzheimers” that was through being part a group called Remembering Yesterday Caring Today where creativity was at its heart. We re kindled love and connection and hope. This conversation is so brilliant THANK YOU. **Kate Swaffer, Kaurna Country**: 🌻

Kate White: I have talked about an expanding sense of self with dementia rather than a shrinkage.

J.O., Chair I think you're all breaking the mould in being open about it. And I think this is the only way. To show people how living with dementia isn't the end of life. That lives continue. You go on growing, developing. And it gives everyone who receives that diagnosis hope, that they still might not get from a healthcare professional. And I think as healthcare professionals, we could do much, much better in giving that hope at the same time as knowing that a diagnosis isn't an easy thing to receive. Gail, is there anything you'd like to comment on before we move to the next section of our meetup?

Gail

Give us Time to Learn New Skills

I think the only thing for me is many people think that we can't learn new skills. But. They should just give us time and be more patient with us because if they give us more time, we would learn new skills and we still can learn new skills, and I proved that.

Kate I think with support, people can still do what they used to do, too.

Gail If that's what they want to do, right? I've proved that I've learned how to paint and how to draw, after diagnosis. And I'd never done that before. Give us a chance so we can learn something new.

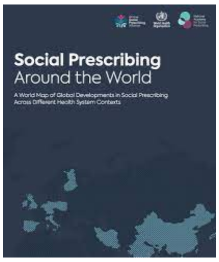
J.O., Chair Thank you. I think the brain is a wonderful, marvellous thing, isn't it. You've all spoken about ways that your brains work, knowing that you have this diagnosis. But you found new ways of seeing things, new channels, as well as continuing things that were already in your life, I do think it's very inspiring to hear. Thank you everyone, for contributing and giving your own angle. Everyone's different. You've all brought so much enrichment to this conversation. Thank you.

CHAT
Keith Oliver: What a great webinar.
Nigel Franklin, A4D: So inspiring!
Veronica, A4D: Thank you all for your profoundly inspirational and courageous sharing - thank you Kate for staying up late to talk from Australia, Wonderful Conversation
Berni God: Thank you so much ! Veronica ! Mostly for inviting me to this real and inspiring people who live with Dementia amazingly ! Makes me inspired to live in the moment and with Joy regardless of what news they have been given !
QJ: Thank to all who have contributed it was very powerful
Tibbs Dementia: such a helpful, hopeful and inspiring morning. Thank you.

ACCESS & SUPPORT

J.O., Chair At this point, we're going to move on to think about access because many people living with dementia may need some assistance to know how to make those connections to get into using the creative side of themselves.

We are going to start by hearing something about social prescribing from Hamaad Khan, who’s a medical student, but not just your average medical student Hamaad is Global Development Officer and he collaborated with the World Health Organisation to author a report on Social Prescribing Around the World. Really looking forward to hearing what you have to say.



Hamaad Khan, Global Development Officer, National Academy for Social Prescribing 'Social Prescribing: Its Place Purpose & Value: For Dementia Care and Patient Wellbeing'

Thank you so much, Jan. It's an absolute pleasure to be here this morning to talk to you all about social prescribing (SP) and galvanizing a student movement for the benefit of dementia care that is more holistic, complete, empathetic and patient-centred.

Paradox of Modern Medicine – More Medicines and More Illness

But first I would like, as a medical health professional to talk about the cultural clinical context that we're in. There's a gaping, huge, daring paradox of modern medicine, which I like to call it. And the paradox of modern medicine is that we live in an age with more medicines, more therapies more treatments and yet also more illness.

Now, if medical drugs are designed to revive, restore and renew good health, we should be experiencing an unprecedented level of good health across our societies. Yet at this time of the greatest scientific medical understanding, it seems ever harder to attain good health, good wellbeing and good nutrition. This goes across the board not even looking at the ageing population or dementia diagnosis.

UK's System of Sick Care

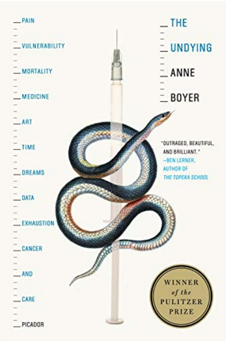
In this context, the UK has created an industrialized healthcare system of sick care, not healthcare. We admit the sick, we tend to the sick, we care for and heal the sick as health professionals. And when we're done laughably, ironically, horribly, we put our patients back out into the very same conditions, environments and lifestyles that exacerbated or perhaps even caused the very sickness in the first place. So a whole system is cyclical, fragmented, acute pep. Our health systems are designed to respond to crises, but they're not yet developed with a vision of health creation and disease prevention.

SP – A Model for Health-Care not Sick-Care

That's where SP comes in. It's about understanding what's the matter with the patient, but also what matters to the patient holding their hand, understanding what the problem is and seeing where we can make those vital social connections to improve a biopsychosocial understanding of their health.

Diagnosis

But in this context, in this horrible, industrialized context, the patient becomes a passive entity. We have heard much already about the burden of a dementia diagnosis and how, unfortunately, you can sometimes have your social networks collapse and you feel this passive sense. We see this a lot in our medical care. A brilliant writer called Anne Boyer talked on her cancer diagnosis and experience of medical care. I wanted to share this because I thought that this may even resonate with quite a few of the audience here today. She said in *The Undying*:



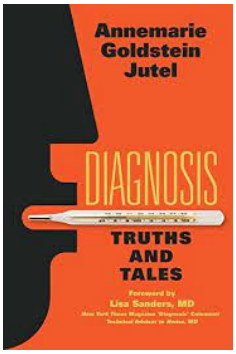
> We fall ill and our illness falls under the hard hand of science, falls onto slides under confident microscopes . . . then there is this body (my body) that has no feel for uncertainty, a life that breaks open under the alien terminology of medicine.

(Boyer, A., 2019, *The Undying*, 18)

She writes beautifully about how empirical science does little to invite respect and care for the patient voice in their journey to a long-term wellbeing and resilience. And that's the key. Because the patient voice is hushed under the hubris of modern medicine.

Listening to the Patient

There's a common phrase in medicine by William Osler, who is considered one of the grandfathers of evidence-based medicine. He said many years ago, ‘Listen to your patient. They are telling you their diagnosis.’ It seems we've stopped listening because now 44.6% of patients want more involvement in their healthcare. And yet at a record high, 10% of patients feel disregarded.



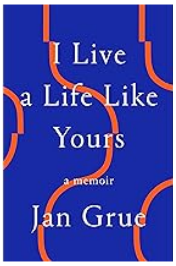
Again on what a diagnosis means and its effects on our patients. It changes how we think about our bodies. Annemarie Goldstein Jutel says our disorders are futures and even our identities. It brings into the foreground consciousness of a body that is sick, complains, creeks, and disobeys our intentions to do what we want to do.

(Jutel, A.G., 2019, *Diagnosis: Truths and Tales*, 18)

But medicine and SP, as it were, can offer far more when we allow patients the dignity and autonomy to direct their own care, to understand how they want to move forward with their life. Because diagnosis is not a fate. It's not a burden.

SP Student Acting with Early-Stage Dementia Participants at Southwark Playhouse (2020)

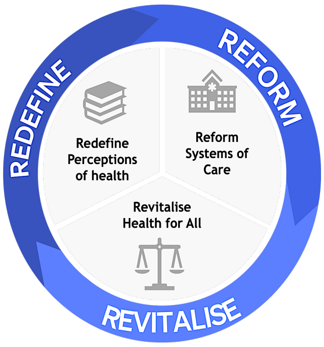
As a neuroscience student a few years ago, I had the absolute privilege of attending an early-stage dementia programme which Veronica organised for Arts 4 Dementia in partnership with the Southwark Playhouse. As a volunteer at these weekly SP drama workshops, I saw dementia beyond my clinical gaze of neurofibrillary tangles or amyloid plaques. I found vibrancy in many people, not just patients, but people who persisted through a disease that is so far easily marked by loss and deficit. I saw patients who weren't encouraged to submit to their symptoms but empowered to improve their own health and wellbeing in a way that makes sense to them. That's what SP is about. It's removing the unnecessary clinical gaze and connecting patients to their community services and resources so that they can also be incorporated and integrated into a wider sense of care.



Jan Grue, the Netherlands writer talks about his cerebral palsy. He mentioned the clinical gaze and says:

> What is this gaze, which is so sharp and penetrating but simultaneously dull and disinterested, that separates things that should not be separated and at the same time mistakes one thing for something very different?

(Grue, J. 2021, *I Live a Life Like Yours,* 30)



SP: Establishing Cultural Change

SP tries to remove a lot of that unnecessary clinical gaze. It's about establishing a cultural change. We want to redefine perceptions of health. As a student, my perception of health was determined by symptoms, diagnoses and biomedicine. But by understanding that patients can improve their sense of wellbeing with a biopsychosocial care,

Every GP has Linkworker to Connect Patients to Arts Programmes

By incorporating a linkworker who can connect them to the community, understanding what sort of hobbies are important, whether it may be playing instruments and improving your sense of wellbeing through different forms of art, as we've heard.

Redefining Perceptions of Health It's about redefining that perception of health, not just for current doctors and healthcare workers, but also for future doctors, current students.

Reforming Systems of Care And by doing so, we reform our systems of care. We make sure that every GP has a vital link worker as we now have in this country, where when patients come in with perhaps symptoms of dementia, not only are they given a biomedical care, but they're also connected to their communities so that they have a holistic sense of wellbeing.

Revitalising Health for All By doing so, we eventually revitalize health for all, by not just unnecessary medicalizing, but vitally socializing, people's connections too.

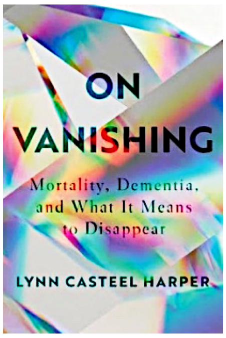
SP Student Champions

Here is our cohort of SP Student Champions. These are healthcare students and also leaders of Change of Tomorrow that is vitally needed understanding that actually clinical care isn't just in the biomedicine, but in the biopsychosocial care. We are excited and empowered to also empower our patients and to not just burden them with clinical diagnosis, as it were.

Mural – Looking Beyond the Pills

This is a beautiful mural that we all created and presented at the House of lords in 2022 on how we have to look beyond the pills, and incorporate a wider understanding of what health can mean and how we can actually invite that patient voice: *What matters to you? What does health and wellbeing mean to you?* And *How can I as your doctor, as your healthcare professional, not just medicalize, but help fulfil that vision of yours?* Because a diagnosis isn't a sealed fate or a burden for you to bear.

So that's SP, the axis of SP. I wanted to end on this note because I thought it reiterated the conversation before and again. A beautiful book by. Lynn Casteel Harper. She writes on Dementia. she said: ‘As the degree of neurological impairment increases, the person unfortunately, becomes increasingly neglected and isolated.’ She calls this the vanishing. ‘The vanishing at the vanishing point . . . is an illusion . . . The person with dementia exists beyond my capacity to keep her in my line of sight.’ And that's what SP is about. It's about keeping our patients in our line of sight and not losing them to unnecessary biomedicine. Thank you so much.



J.O., Chair Thank you very much. I think that will be very inspirational for people who work in health and social care. Where we have the weight of medical biomedical tradition on our shoulders. I think by working with other medical students to break out from those confines and be able to see the people that you work with, I think that that can make a real difference if you can shift that culture. So thank you very much for your words.

CHAT
QJ: Harmaad.what gaps do you think we need to bridge to improve the links between Art & Health and social prescribing? Thank you **Hamaad, @HamaadAKhan**: ."Thanks QJ. I think in part its (1) educating healthcare workers to recognise this now evidence-based pathway to wellbeing, (2) developing sustainable funding models to create capacity in communities to upscale their programmes - but the crucial link is already there with link workers. Every GP practice now has a LW, referred to by the GP if recognised that the patient can benefit from a social prescription
Jane Troughton: Brilliant!
Wendy:Refreshing to hear Harmaad 🙌 **Hamaad,** ❤️
Alison Canty: Thank you for a fantastic session.
bisakha sarker: Such clarity of thoughts from Hanaad **Hamaad** ❤️
Veronica, A4D:Thanks so much Hamaad - such an important widening of understanding to clinicians. It is truly wonderful that GPs can from the outset guide patients towards social prescribing link workers who can direct them to local empowering arts. Warmest thanks, **Hamaad**, ❤️

J.O., Chair And our next speaker in this part of the programme is Tessa Gutteridge. Tessa is the person who started the Young Dementia Network, which has been going for several years now in the UK. She worked to improve things for people living with YOD for many years before that, too. Tessa is going to talk a bit about how people can access the Network if they're living with YOD or working with people with YOD.

Tessa Gutteridge, Chair, Young Dementia Network and Programme Director for YOD, Dementia UK

Thank you. However many years I've worked with YOD. I'm realizing every day, this morning included, there's just so much to learn. So much to rethink.

I've just thoroughly loved this conversation so far, so thank you very much for including me. I think most of the contributors today. have played a part in the Network, either on the Steering Group, or take a part in our activities. So you know us well, but for those of you who don't know us, thank you very much for the opportunity to tell you a little bit more about the Network.

Young Dementia Network

We're a collaborative community of over 5,000 members now. We're united with a common purpose, that's around improving lives of people with YOD and their families. We want improvement now, of course; and we want to bring about significant change for the future.

Membership

The broad membership is an amazing blend of people. Just over 40% or so are people with lived experience; and then the rest are professionals from Health and Social Care – a range of roles, really, including Admiral Nurses, clinicians, service developers – and then academics and researchers and then people who are interested in YOD. The Network is steered by people with a passion for change – vocal activists with networks of their own, professionals from dementia organizations and academia. All volunteer their time and expertise. I don't know what we would do without them. There are just three staff who are very motivated. And to be honest, we're driven by personal experience ourselves too.

We set up, as Jan said, a few years ago, back in 2016. This was really because awareness of YOD and the information and support from pre-diagnosis onwards was nowhere near good enough then – and still nowhere near good enough now. And although I would say that there has been some progress made in some areas, there's such a lot of variability.

Current aims:

To Improve Diagnostic Experience

Our current aim as a network, and where we're most active this year, based on feedback from people with YOD, is around improving the experience of diagnosis, for the person and for the family. The route to diagnosis can be very challenging.

Increase YOD Profile and Lifestyle Support

Alongside that, we're really keen and we need to do it alongside, of course, to increase the profile of YOD amongst public and professionals. When something substantial has happened there, we want to increase access to lifestyle support. That's another part of our aim. That needs to change, of course, as you know, as needs and wishes alter along the way.

Working in Collaboration – does the Network have a part to play in Creativity?

In this and all our work, we work collaboratively. We don't feel that any one group or organization has all the answers. We definitely feel stronger if we work together, both nationally and internationally. But I did wonder when Veronica invited me to be part of this conversation, does the Network have a part to play?

Creativity in our lives

I especially feel that now after hearing the amazing creative contributions from people who live with YOD and who know what they're talking about in terms of what creativity means to them. I do understand intuitively the vital part creativity plays in all our lives, whether we have a disability or not. And the prospect of this conversation made me think about what part creativity plays in my life. We can get wrapped up in work and general everyday personal stuff, can't we? It gave me an opportunity to think about that. It’s a running joke in my family that the cross-stitch cushion cover with pretty rosebuds decorating it which I started in order to mark the birth of my only daughter Rose is still – 33 years on – not finished, it's nowhere near finished. In truth, that does not give me joy, so that made me think, well, where am I creative? Creating dishes for family and friends to share, creating a beautiful garden again for family and friends to share with me. This all gives me pure pleasure, and I feel it nurtures a very different aspect of me that needs to see the light more and more.

Turtle Key Arts music workshops

Closer to home, through the YOD Oxfordshire group, I've witnessed the blossoming of people with dementia who were previously very tightly buttoned up, especially in terms of their communication and connection with the world around them. They took part in the Turtle Key Arts Workshops over a number of years. That covered music and singing, dancing, poetry. and it was absolutely wonderful.

Arts participation for brain health to ease meandering peri-diagnostic stress

So thinking of the Network, I don't think that improving the diagnosis experience or improving the understanding and awareness of YOD is an essential precursor to a person accessing their creative spirit. But I do think that reducing the stress associated with the lengthy and sometimes meandering route to diagnosis matters. Knowing what you're dealing with, being able to have easy access to a professional who you can trust, and having sound ssinformation along the way, I do think is really important. And for those around you, family, friends, employers, community, to be able to recognize, accept and welcome you as yourself, with YOD and put up no barriers to participation in joining in or in pursuing your own life-enhancing, creative opportunities. I really feel that's important, too.

I think that aims that the Network pursues and the work it's doing should support the person with young onset and so contribute to enabling the mind space, time and energy for creativity to flourish. I think it's that work that the Network is involved with. I also feel that the photos, pictures, the sketchings, poems, music, the wonderful books that people with YOD create and share actually motivates and lifts the spirits of the people who work in the field as well – people like me and my colleagues. So don't underestimate the value of that. That's absolutely marvellous. Thank you. Thank you for giving me the opportunity to be involved in this.

CHAT: Tessa Gutteridge: Young Dementia Network website and Join up form: YDN YouTube animation (1 min 40s) explaining the Network from the perspective of a person with YOD.
Alison Watson-Shields: Thank you so much for sharing such interesting, engaging and thought provoking content.
Veronica, A4D:Tessa, it is so valuable to know of the support you give through the Network and of your openness to creativity - as you say, sharing nutrition and gardening brings such uplift. And reducing stress over the peri-diagnostic process is so important, especially in YOD which takes so much longer. We shall do our utmost through Arts 4 Dementia to signpost arts opportunities for dementia nationwide.

J.O., Chair Thank you very much. Tessa.

To Be, or Nsot to Be Open About Dementia

It's been inspirational to hear members of the panel; and that I think you're helping us break through you’re helping the people living with YOD to break through that catch 22 where if you're seen to talk about the things you can do, people then accuse you of not having dementia. But by being open about your dementia, you are showing both that you do live with this unwelcome guest but also that you find ways to flourish and you contribute a great deal to society.

So I think the work you're doing is really pioneering and trailblazing. And it's been just very enriching to hear about it.

Veronica, A4D, Host I want to thank you, Jan, for your expert chairing of our Young Onset Conversation. You yourself, and Tessa, enable so many people with young onset to flourish by the very powerful work that you do. We are all enormously grateful and privileged to have you as chair, generating rare and valuable insights from our courageous, talented and inspiring speakers today.

Tragically, I felt it significant now to raise awareness of how music helps children whose lives are curtailed by Batten Disease, of which dementia is a symptom, through the leading authority of our final speaker Professor Adam Ockleford.

Adam is a music psychologist based at the University of Roehampton in London. His research interests include the impact of different neurological conditions on the development of musical abilities in childhood, and, conversely, the potential of music to mitigate the effects of neurodegeneration. He has worked extensively with children and young people with Neuronal Ceroid Lipofuscinosis (NCL) or Batten Disease. Symptoms include blindness, epilepsy, and the decline of speech, language, and dementia. Adam led a three-year project that examined the potential role of music in enhancing the lives of children and young people with NCL – it has been deeply moving to see the remarkable effect he has on such challenged children. It will be really interesting to hear from you, Adam.

Adam Ockelford, Professor of Music, University of Roehampton, ‘The potential role of music to enhance the lives of children and young people with Neuronal Ceroid Lipofuscinosis (Batten disease)’

Thank you for inviting me to talk briefly about the potential role of music in children and young people with either juvenile or infantile dementia, which is very rare, but it does affect a few hundred children in the UK at any one time.

One of the symptoms of juvenile dementia can quite often be blindness. And this is where my interests overlap because I run a charity called The Amber Trust, which supports children and young people who are visually impaired to make music. We studied twelve young people, very much with the support of their families and their teachers. They were across the age spectrum from early years to later teenage years and had a whole range of stages in their journey through Batten Disease.

The potential role of music
to enhance the lives of
children and young people with
Neuronal Ceroid Lipofuscinosis
(Batten disease)

A report on a three-year
research project undertaken
by the Applied Music
Research Centre at the
University of Roehampton

Adam Ockelford
Rebecca Atkinson
Katya Herman

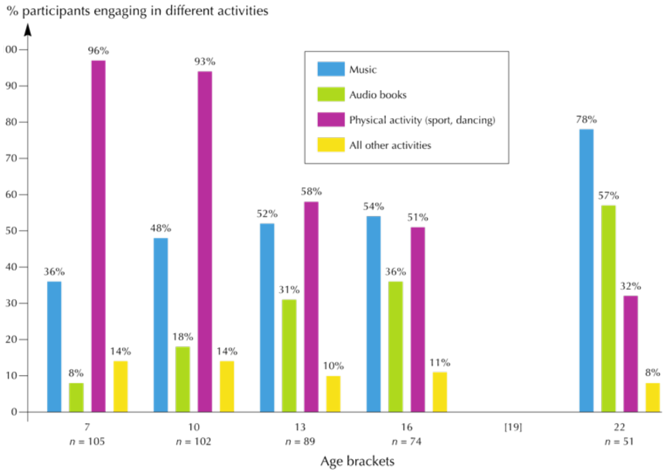
University of
Roehampton
London

Musical stimulation - key findings

Brings pleasure even at end of life: The key findings were that the capacity to engage with music declined more slowly than their other abilities. Even at the end of their lives, it seemed that music could still bring them pleasure – as well as offering social opportunities for them to remain part of their families, which was terribly important.

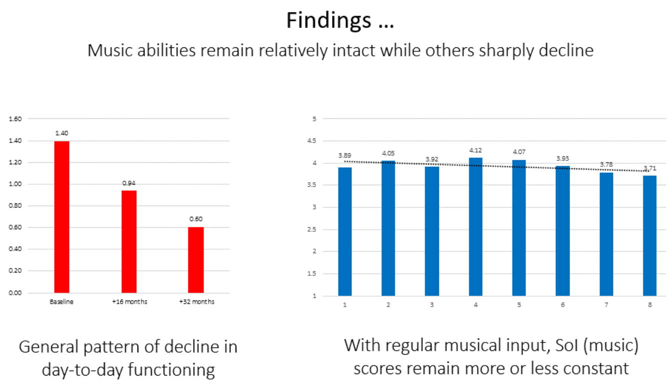
Can stimulate otherwise inaccessible memories As with older people with dementia, it seemed that music could stimulate memories that may otherwise be inaccessible.

Microsongs extending communication by up to four years We felt strongly that active encouragement to engage with music was important in the earlier stages of the disease. So adopting a pre-emptive approach. Almost universally, we found that children could continue singing when they could no longer speak. And we devised some special microsongs or short, functional songs that contained everyday language such as *No, thank you* and *Yes, please* which was a way of extending communication in some cases by three or four years.



Above all, music was a source of great pleasure to many of the young people. we worked with, promoting wellbeing and emotional regulation.

Here are some of the findings. What we found- this is from parental reports - was that while music was of average importance for seven-year-olds who are in the early stages of the disease. By the time the Juvenile Batten Disease



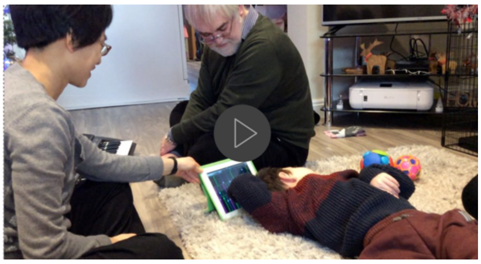
Findings …

Music abilities remain relatively intact while others sharply decline

General pattern of decline in day-to-day functioning

With regular musical input, SoI (music) scores remain more or less constant

patients were older, music became incredibly important. In about 80% of cases music was the main source of leisure activities, along with audiobooks, slightly less so. There's a change in the kind of leisure activities that children and young people with Batten Disease go through as their journey progresses. And here's the evidence for the continuation of musical engagement. You can see over the three years of the study. The children's capacity to engage with music stayed more or less. constant while overall there's a general pattern of decline in day to day functioning. Then a couple of videos, just to show some of this in action.



Here is Ollie. Ollie has lost many of his abilities. In fact, he never got to be verbal. But music was very important to him. And here he is playing, interacting with me by using an app on an iPad, which he plays with his elbow. Here we go. Ollie lies on his back while Adam sings gently *‘Ollie play that song / While we sing / Ollie play the song / All join in / Ollie play that song / While we sing.’* Ollie turns over, and at the end of each line, touches the iPad behind him with his elbow, making the screen sparkle and play trinkling electronic music.

In fact, technology was incredibly important. The Amber Trust is currently sponsoring. Technology in Music Education (TIME) to create a new sound beam, a sort of ultrasonic beam through which children who can perhaps just move a finger will be able to engage with music-making.

Here's Lily who I worked with for several years at the end of her life. Lily had lost the ability to speak when I knew her, but she could still sing. Here she is expressing first of all her preference for something to eat and drink. Both are seated at the piano, Adam plays and asks *What you like for breakfast, Lily?* As she answers, Lily claps merrily. *I would like some breakfast … I would like some … I would like some Weatabix*

What would you like for a snack Lily. I would like some fruit.

What would you like to drink Lily. I would like some squash.

Here's a song with Lily expressing her feelings which are very important.

How are you feeling? How are you feeling. How are you feeling today. Happy Happy Happy Happy Happy Asked to ask Adam, *How are you feeling?* He replies. *I'm feeling Happy Happy Happy!*

Lily was an extraordinarily happy person and a great inspiration to work with.

And finally, With Music in Mind working on the project helped us think of the place of music in the children's lives. The inner Circle is about listening. Playing and singing and making music with others. Then the Outer Circle was the broader effect of music in supporting, remembering. Understanding, moving. Communicating socializing and feeling. And indeed, I'm involved in a project with older people with dementia, now called Take Note that uses that framework.

Veronica, A4D host

Thank you, Adam. That was so incredibly moving. It's so important that we know about juvenile dementia and that involvement with music can extend communication by three to four years – oh so valuable with children. Thank you very much for opening our eyes. This is just a start for us. I hope that we shall have a special, dedicated event in the future. Thank you very much and thank you all for coming, to Jan our chair, to our inspirational speakers. We do look forward to welcoming you again to take forward action points raised today. For anyone on the call with YOD, you will find links for support through Tessa's Young Dementia Network – and do give the arts a go – Gail, I can't believe you have had no art training, only taking it up after your diagnosis. If you live in Kent, look out for Chris playing his tenor horn on bandstands at the weekend. As I write this transcript, Gail and Wendy's blogs fly in, Kate it was fantastic to hear Wendy say that your example gave her Hope. Keith you generously give guidance all over the world. Thank you to the Arts 4 Dementia team, my brother Nigel Franklin for overseeing the technology, and to our series Coordinator. Finally, to Jan, warmest thanks for your research strength and generosity in steering our Greengross A4D Global Arts for Brain Health Changemakers – Young Onset – Conversation today. Changemakers indeed.

*** Our next Greengross Conversation will focus on the impact of art – and a garden! - in Rare Dementias, to be chaired by Professor Sebastian Crutch of UCL, on Thursday 18th January 2024 ***

If you know of anyone with a Rare Dementia who would like to tell us how art, dance, music, drama, poetry . . shines for them – wherever in the world – here's my email: veronica@arts4dementia.org.uk

CHAT

Jan Oyebode: It's been such a pleasure to meet you Kate - thanks for coming and contributing

Kate Swaffer, 😘

Wendy: Lovely to see and hear you again Kate 🤗xx **Kate Swaffer,** 🌻🌻🌻

Jan Oyebode: Thanks again Veronica for inviting me to chair - thanks to the star-studded inspirational panel members and to Hamaad, Tessa and Adam.

Kate Swaffer, Kaurna Country:I'll hang on to listen to Adam … juvenile dementia is such an important topic. thanks everyone, for such wonderful contributions too

Caroline Welsh: Thank you so much for a wonderful session..

bisakha sarker: Veronica you are Amazing **Kate Swaffer,** 👍🏻 **Veronica, A4D** ❤️

QJ: Thank you so much for today’s webinar has been very enlightening and I would like to thank all the speakers. **Lucy Szablewska**: Such an interesting session - many thanks!
Sabrina Ahmed: Really enjoyed this session, such great speakers, thank you!
Kate white: Thank you Veronica and colleagues especially those with lived experience sharing your moving stories.
Julie Allan: this has been so heartening, thank you all so much
Laura Cleverley: What a powerful webinar, thank you so much to you all for sharing! I feel very moved too Veronica
Tanya Duckworth: Thanks for the invitation to join today It’s been a wonderful session!
Kerry-Ann Stanton: thank you, moving and informative indeed
QJ: Thank you Veronica and all who have been involved
Kathryn.Sams: very interesting session, thanks to eveyone who has shared their story, or presented, as a health professional has certainly given me lots of inspiration, thank you
Carol Victoria: It's been incredibly informative - Thank you all!

CONVERSATION 3

Rare Dementias Conversation: Thursday 18 January 2024

Rare Dementia Support
Advice Community Learning

VERONICARTS
Arts for Brain Health

AGE
IRRELEVANCE

Arts 4 dementia
Empowerment through artistic stimulation

Greengross 'Rare Dementias' Conversation (Thursday 18 January 2024)

Rare Dementia Support UK provides support for seven rare dementias: Posterior cortical atrophy (PCA), Primary progressive aphasia (PPA), Frontotemporal dementia (FTD), Familial frontotemporal dementia (FFTD), Familial Alzheimer's disease (FAD), Lewy body dementia (LBD), Young-onset Alzheimer's disease (YAD).

Personal expression through creative activities, whether reviving or learning afresh, spending time in nature and with others, enables enduring sense of achievement, or hope, of connection.

This Conversation, chaired by Professor Sebastian Crutch, Professor of Neuropsychology at the Dementia Research Centre, UCL Institute of Neurology, will explain the neuroscience and present a range of research, lived experience and practice in the UK members of Rare Dementias Support UK speaking on the impact of their chosen arts, Sweet Patootee Arts giving the Caribbean perspective and Eloisa Stella and Cristian Leorin of Novilunio in Padua, Italy discussing their rare dementias arts programme and their members discussing and campaigning for arts support for rare dementias in Italy

70 **HOST**

Veronica Franklin Gould, President, Arts 4 Dementia.

72 **CO–CHAIRS**

Professor Sebastian Crutch, Professor of Neuropsychology at the Dementia Research Centre, UCL.

Charlie Harrison, Rare Dementia Support (RDS) Creative Consultant, 'Rare Space: Celebrating the creative and cultural lives of people affected by rare dementias.

78 ***Do I see what You see?*** film directed by Simon Ball for Created Out of Mind.

PANEL

80 **Helena Clarke**, artist living with PCA, choral singer, enjoys choral singing and garden rewilding with her husband **David Clarke.**

85 **Chris Chadburn,** living with logopenic variant PPA, and **Andrea Chadburn**, who together enjoy a wide range of arts.

88 **Tony Thompson,** Chief Executive, Artistic Director and **Rebecca Goldstone**, Co-Director and Producer, Sweet Patootee Arts.

91 **Monica Boulton**, NASP Healthcare Integration Lead.

93 **PANEL DISCUSSION**

99 **Eloisa Stella,** President, Novilunio, Padua, Italy, interviews

100 **Tiziano Tracanzan**, advocate living with YAD, shares experiences and reflections on museum and cultural visits in Padua and Chioggia.

102 **Cristian Leorin**, adjunct Professor at the University of Padua and the University of Modena-Reggio Emilia, co-founder and Vice-President of Novilunio, discusses the objectives and content of group meetings with people with rare dementias in Padua.

102 **Francesco Parisotto**, who lives with Cadasil, reads three poems and speaks with Cristian about the impact of poetry and writing on his wellbeing

THE CONVERSATION

Veronica Franklin Gould, President, Arts 4 Dementia

Good morning and welcome to our speakers and delegates from around the UK – from Australia, Austria, India, Italy, the Netherlands, Portugal, Taiwan, and from the United States of America.

More than 55 million people worldwide, 944,000 in the UK live with a rare, inherited or young onset dementia, of whom between 5% and 15% receive a diagnosis. These conditions tend to occur at a younger age than the more common form of Alzheimer's disease and can cause symptoms that are not only memory-related, for example, difficulties with vision, language, movement and behavioural changes.

Today’s Conversation will be chaired by Professor Sebastian Crutch, Professor of Neuropsychology at UCL and will be co-chaired by his Rare Dementia Support RDS Creative Consultant Charles Harrison and for the Italian perspective, Eloisa Stella and Dr Cristian Leorin of Novilunio in Padua Italy.

Rare Dementia Support provides for seven rare dementias: Posterior Cortical Atrophy (PCA) Primary Progressive Aphasia (PPA), Frontotemporal dementia (FTD), Familial frontotemporal dementia (FFTD), Familial Alzheimer’s disease (FAD), Lewy Body Dementia (LBD), Young-onset Alzheimer’s Disease (YAD).

Personal expression through creative activities, whether reviving or learning afresh, spending time in nature and with others, enables enduring sense of achievement, or hope, of connection, as case studies on their inspirational Rare Space website illustrate - and indeed our Italian team. Their members each living with a different type of dementia are going to give us insight into how engaging with their chosen creative and cultural activities enhance their lives

We shall also hear from Tony and Becs, Co-Directors of Sweet Patootee Arts, whose film *The Turning Point* gives the Caribbean perspective, the importance of heritage and arts-based support.

On the question of access, participants can join arts programmes for their rare dementias at any stage in their diagnostic journey, chiefly through neurological referral and the marvels of Googling Rare Dementia – But on a personal level, the growing availability of social prescribing link workers through an individual's GP to address a person's wider, social and cultural needs can ease access to these arts to preserve brain health, from the outset of symptoms, but at any stage. Monica Boulton of the National Academy for Social Prescribing will explain.

Before handing over to Seb, I should explain that the instigator of this Changemaker Conversation series, Baroness Greengross, was passionate about the need for music and the arts to be embedded in the health and social care system for dementia. Sally, our dear friend, Arts 4 Dementia patron and Co-Chair of the All-Party Parliamentary Group on Dementia, worked indefatigably to advance arts for brain health strategy in Parliament.

We are truly grateful to our speakers whose guidance inspires best practice in arts for brain health the world over, to Nigel Franklin of A4D for technological wizardry and to uur colleague Amisha who will keep an eye on and preserve the Chat and help edit the recording for an online resource, together with this transcript. If you would like to upload your own resources, we shall add those too.

Now, I should like to introduce Professor Sebastian Crutch. Seb **i**s Professor of Neuropsychology at the Dementia Research Centre, UCL Institute of Neurology and is the RDS Clinical Lead. His research focuses on rare and young onset dementias, especially PCA, the 'visual variant' of Alzheimer's disease. The work has led to improved understanding of dementia-related visual impairment and the causes and consequences of atypical Alzheimer's more generally. From 2016-18, Seb directed the Created Out of Mind residency at Wellcome Collection Hub, bringing together artists, scientists and people living with dementia in a collaboration of over 60 individuals, institutions and charities aiming to shape and enrich public and professional perceptions of the dementias, and to explore the opportunities afforded by collaborative, interdisciplinary, publicly situated research.

Seb, it is an honour to welcome you as chair.

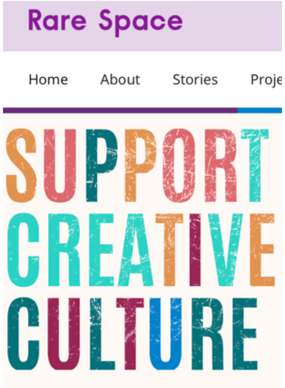
Professor Sebastian Crutch, Chair **Charlie Harrison, Co-Chair**

Professor Sebastian Crutch, Professor of Neuropsychology at the Dementia Research Centre, Institute of Neurology, University College London.

Thank you ever so much and thank you to you all for being here and to Veronica for inviting us. And yes, it's an honour to do anything in Dame Sally's name. So a real pleasure to contribute to this. I hope you can see on screen with me my dear friend and colleague, Charlie Harrison.

Just to explain the format for this afternoon. The idea is to keep this very informal and discursive. We will be sharing ideas, inspirations, anecdotes, a few facts along the way and generally talking a little bit about how our work in dementia and the arts has come together and conjoined. And most importantly, hearing from people living with or supporting someone and caring with and for and about someone who's living with a diagnosis of one of these rarer dementia conditions, to understand a little bit more about what it really means to engage in the arts and what some of the benefits and the impacts can be. So Charlie and I will just kick this off a little bit.

Charlie, I wondered if you might introduce yourself to everybody. Then we're going to ask each other a few questions for the first 15-20 minutes or so.



Charles Harrison, Co-Chair, RDS Creative Consultant, 'Rare Space: Celebrating the creative and cultural lives of people affected by rare dementias'

I'm Charlie Harrison. Thanks very much for inviting us to bring this together today. We're really looking forward to opening up these conversations. Seb and I don't get loads of opportunities to share some of this work and it's really nice to be able to hear from our members and to talk about arty things. I'm a visual artist by background and got involved in this area of work about ten years ago. I currently coordinate Rare Space: which is a new part of the RDS service. We're particularly interested in the creative and cultural lives. of our members and thinking about how these things impact on people's everyday life, bring about positivity and change as people adapt to their changing circumstances.

‘Rare’ Dementia

So, Seb, I was going to ask you a few questions to start off with, and I suppose the obvious one to start with is, what do we mean when we say ‘rare’ dementia?

SC Thank you. We often get asked why we use the word ‘rare’, because it seems to suggest that this is a niche interest. By ‘rare’ we mean atypical, ie, non-memory-led dementias, young onset dementias. So people living with conditions where the symptoms or the diagnosis happen before they're 65 and also inherited forms of dementia. Obviously, all of us are at some degree of genetic risk or greater likelihood of developing a dementia at some point in our lives.

Inherited forms of dementia

But there are some, relatively, mercifully relatively few, but still some families who live with a specific mutation in their family that gets passed from generation to generation, with 50% of all siblings in any generation being likely to get the condition if one of their parents has carried the gene. So directly inherited forms of dementia and rare dementias are those which don't typically fit with most people's stereotypes or assumptions about dementia.

I think despite great awareness building, there still resides the temptation to think, or to associate dementia with much older people and with memory. Many of the people we work with buck one or both of those assumptions. But by rare, we actually often don't mean it's not necessarily that numerically infrequent.

15% of all dementias in UK, 145,000 people – rare, but not that rare

We're probably talking about 15% of all dementia not being so-called typical late-onset Alzheimer's disease or vascular dementia, which are the two dementias which most people have heard of. 15% in the UK, that's about 145,000 people. So they're rarer, but not actually that rare. But sadly, many people don't ever get that diagnosis. Still, many people are told you've got dementia. No more information than that, or a diagnosis would be given of Alzheimer's disease, perhaps not recognizing some of the more specific early features.

CH, co-chair Thank you. That's really clear. I remember when I first started being involved with this, never really having any awareness around it at all. I feel it's a really important part of our message to share this information. We hear a lot about very particular challenges that people face because of some of the issues you're talking about, about how difficult it can be to get a diagnosis, for example, and also because of some of the quite particular symptoms that people have. Could you tell us a little bit about some of those challenges that are quite specific to this area.

SC, chair As Veronica mentioned in the introduction, we work with lots of people whose dementia presents not with difficulties with memory, but difficulties with vision, with seeing what and where things are, with problems with language that might be understanding what is being said to them or what they're reading, or being able to produce language and convey messages in the way they want to. Some dementias, particularly when attacking the front of the brain, cause distinct changes in people's personality and behaviour. People, perhaps, who might be more socially disinhibited, unable to follow the social rules or norms in the way that they normally would, and so do or say things or don't do or say things that they would otherwise have done.

Rare – meaning precious

So I think when we're thinking about challenges and going back to your first question about what do we mean by ‘rare’, we also intentionally use the word to mean precious, because I think many people, most importantly, including some of the people you'll hear from directly in a few moments, are able, because their dementia starts with something other than memory, to give us very generous and informative insights into what many people with any kind of dementia at any age may experience, perhaps a little bit later in the course of their dementia. For example, the majority of people with late-onset memory-led Alzheimer's, will also develop problems with vision and with language at a later stage, but perhaps at a stage when they can't necessarily explain or communicate that to other people or have insight into it themselves.

Educational message

So I think what we're hearing about today is not just stories of a personal nature, but stories with a really important educational and public awareness-raising message that we can't just think of dementia as presenting the challenges that it does initially.

Sadly, all of these are progressive diseases. So the challenges people were facing and the adaptations, therefore, when engaging people in different artistic and other opportunities, will need to constantly be on our toes to adapt to those challenges.

CH, co-chair I think that's been such a clear part of being involved in this area of work, that creativity is involved and threaded through so many different aspects of how we meet those. You're not just a psychologist, you spearheaded this two-year residency at the Wellcome Collection, Created Out of Mind (2016-18), and had a previous research interests and background with artistic work and creativity.

SC, chair As you say, I'm by no stretch an artist, but very early, you said that you fell into this area a little bit by chance. I feel the same, that I had the great privilege, within months of starting work at the Dementia Research Centre in Queens Square back in 1999, of meeting the visual artist William Utermohlen (1933-2007), who had recently been diagnosed with Alzheimer's disease and was very generously taking part in a number of research programme. To get to know him and his wonderful wife, Pat (art historian), and to understand a little bit about their story and how his experience of that condition were expressed through quite a now famous series of self-portraits that he painted and drew in the subsequent years. So that was my introduction.

Insights from people living with rare dementias

But thinking about creativity more broadly, almost all the research that I've been privileged to take part in or to lead, has been in some way inspired by or shaped by the experiences of people doing what you're about to do, of talking to people who actually know really what they're talking about. People would very generously refer to me as an expert in dementia, but that's an expertise which is derived almost entirely from the great privilege of speaking to hundreds of people with these so-called rare conditions and therefore, being able to build up a picture, a blended picture, from all those different experiences and all those individual differences of what the common features of these conditions are. So often it's people describing something that we've never heard of before, a difficulty with balance or perceiving where something is, or understanding a particular category of words or knowledge that has inspired us, sparked us to think of a new question or a new technique.

Creative approaches for dementia – a logical tool, not niche interest

As you know so well, Charlie, the dementias affect every aspect of life – personal, social, thought-based, emotional based. Our sensations can also be altered or the way we interpret them. So, I think the drive to involve creative approaches is not a choice or a niche interest, it's just a logical move that when you've got a set of conditions that can affect any aspect of human experience, why would we close off any tools at our disposal in order to try and understand what it means to live with that condition or to care for and about someone who does?

It would be good if I asked you a few questions, Charlie, if you don't mind. Obviously, you've said that you're an artist. I wonder, in particular, if you could just explain to people a little bit about what got you involved in this area. But most importantly, given it's been a few years now. What's kept your passion and your drive and your resilience to work in this area?

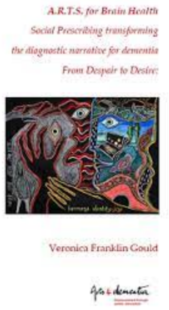
CH, co-chair As I mentioned, it happened by chance that you and I were paired up for this project ten years ago called Art Neuro, which was a project that just paired up artists and neuroscientists to see what might come out of that. I remember one of the first things you showed me was some of the visual processing tests that are used for assessment in the diagnosis of some of these rarer dementias. I found them quite fascinating because they seemed to have a lot of links to artworks as well. That first project, although it was quite small, wasn't just an artistic interpretation, some paintings made based off some of those visualizations.

I have to say I didn't have a personal relationship to dementia, as so many people do who come to be involved in this area. It's often you've had a family member and that's a real driving force for it. I actually think that's important as well, that people who don't necessarily have that personal connection also don't feel that they're excluded from being involved in this area. I think at some point everyone's going to be touched by it and it's important that people do engage with it. Also, over the years I have developed a bit of a personal relationship with it because I've come to know and love so many amazing people who we work with.

Building relationships to build resilience through arts

Just to answer what's keeping me involved in it. Well, it's lots of things, really, partly that developing and building relationships with people, like seeing how important it can be to share their own creativity and how that helping people adapt and things like that, can really build resilience. It's very inspiring to work with people and see how they meet the challenges head on. That's an amazing thing to see every day.

Also, all of our colleagues, such as yourself and others at the Dementia Research Centre and RDS, they're just so amazing and far more difficult tasks in our support team than I have. It's really amazing to work as part of that team. Everyone's heart is really in the right place and people work really hard and also it's very supportive environment. Whilst we provide support for others as well, we provide support for each other and that's an amazing way to work.



From a more personal perspective, it's a real opportunity to use my own imagination as well. Creative health, when we were first starting wasn't so in the public domain, and now it feels like a lot of people are engaging with creative health and how important creativity and the arts can be for people's brains, brain health. So there's a lot of opportunity out there, in terms of unexplored ideas and a lot of people coming into this area. It is interesting to work in an area where there is so much potential.

Interdisciplinary nature of dementia and the arts

SC, chair Absolutely. and Charlie, I just wanted to put one word you use which maybe helps people to understand a bit about the of interdisciplinary nature of dementia and the arts work, in that we don't just sit in our camps with me only thinking about science. And you use the word ‘assessment’, which I think most people would assume would be a me kind of word that I'm constantly doing, conducting cognitive tests or brain scans with people. Whilst you might pooh-pooh that and want them to express themselves. Can you just say a little bit more about where that intrigue or that interest in the notion of ‘assessment’ came from or parallels that you drew with your own work?

CH, co-chair I suppose for me it was just what I particularly found interesting from my own artistic perspective. But over the period that we've been working it, I also became very aware of two things. Assessments are, I feel, a really important way of how neuropsychologists, how the human race has come to understand how the brain works, but it's a very blunt tool as well. And over the time I've spoken to people, whenever I say to people living with rare dementia is, *Oh, I'm interested in assessment*, or that's been part of my work in this area.

People have so much to say and the vast majority of it isn't that positive, as everyone knows. It's an experience that so many people are familiar with, being in that situation where it's quite stressful and you feel quite put on. And whilst the assessments often give us a quite clear picture about some of the things that people might be finding challenging, they also don't necessarily give us a really clear picture of how that applies to people's everyday lives and the sorts of things they might want to be doing, like painting or going out in the garden or like seeing family members and things. And because there is this relationship between assessment and art, I feel, I think, that for me, that was a particular area where we might be able to find some real interdisciplinary ways forward, and we don't have time today. But the research side of my role has developed quite a lot with that area in particular, thinking about how painting and drawing can offer ways of understanding people's experience that also don't shy away from how unique everybody is and how we can express that variability in a way that also builds a clearer picture of the experiences that people are going through. So, yeah, if I start talking about any of those projects I'll be going for, I should probably leave.

SC, chair Well, that's fine. With this transcript, we can circulate a link to information your Talking Lines as an example of that - a project in which is really using drawing to complement other forms of interview by which researchers like me would typically try to get at people's experience of what works and doesn't work and is challenging living with or caring for in this situation. But that's great. Thank you, Charlie.

Rare Space

Veronica mentioned at the beginning about rare space, which is part of the rare dementia support service. Could you just say briefly what that is, just a little bit of context?

CH, co-chair Having done work for a few years in this area as an artist who's finding ways to represent and work with and collaborate with researchers and people with lived experience, I became increasingly uncomfortable that, as you say, the most important thing is to hear from those people. And through working with people, I realized that there's so many creative people in our membership out there who are doing amazing things and finding ways to meet their challenges. So, we wanted to prioritize that a little bit. I think in some ways that came out of lockdown.

Creativity Club During COVID we ran a creativity club where a group of people came together to meet online. It was incredible to see how much it meant people, and that they were learning new things and finding new skills and meeting new people. There were a lot of things, like building social connections and peer support and sharing their stories with others as well.

Social Prescribing Partnerships

We wanted to find ways to share those stories with wider audiences and also look for new partnerships with other organizations, in line with social prescribing. So we've had partnerships with places like the Wildfowl and Wetlands Trust. Last year, there was

a Garden at Chelsea Flower Show, which co designed with people living with PCA, which we're going to hear a bit more about. There's also a project with Wigmore Hall, 'Out of the Ordinary', which has been an ongoing project based, about providing opportunities and linking people up with opportunities that might be appropriate for them, encouraging people to try new things and to think about new areas of research as well.

SC, chair Great, thank you, Charlie. That's really helpful. We'll return to a few of those themes in a moment, but I think before you're going to be interviewing Helena and David about their experience of living with PCA,and particularly their involvement in different artistic and creative activities.

Ask not what disease the person has, but rather what person the disease has – both

We just wanted to show you all a short film, or just a segment of a short film. The reason for showing you this is, I guess, one tension in the dementia and arts field sometimes is between the sciency bits and the artsy bits. And I don't really buy that as a real tension sometimes. Certainly, when I'm reading dementia and arts literature, I feel a little bit scolded. Sometimes people talk about the biomedical model, and I think that probably applies to people like me working in a neurological institute. I often use a quote by the Canadian physician Sir William Osler (1849-1919) '*Ask not what disease the person has, but rather what person the disease has*' We tend to try, and whilst I agree with that, also try and modify it a little bit to say, well, why don't we ask both who the person is and what the disease is? Simply as a way of not anticipating who the individual is or what's important to them, but just understanding a little bit of the context in which they live and some of the challenges that they might be facing, and therefore some of the ways in which we might want or need to adapt some of the offerings that we make and creative opportunities that we provide.

Do I See What You See?

This is a short film. So, case in point is, as Helena will say for herself in a moment, she lives with this condition, Posterior Cortical Atrophy, which literally means back of the brain shrinkage. But rather than having me lecture you about what PCA is, I will tell you briefly that it is literally, as it suggests, it's most commonly a form of Alzheimer's disease, where those proteins affect not the memory centres in the middle of the brain, but the visual centres at the back of the brain. To start with. But, as I say, much better than me talking about it is to show you a few moments of a short film by the filmmaker and animator Simon Ball, in which he has responded to people's lived experience, descriptions of the condition. And that's what you'll hear a little bit of just now.

An ordinary eye test won't necessarily show much. Iso if you're looking at A B D E F that's not a problem. But if you're trying to read a line,

- *I get the first word, and when I go on to the second word, first word's gone.*
  Some from this sentence and some from this sentence, and then coming back up to this sentence, blobs on a piece of paper.
- *Everything does dance around all the letters and eventually just becomes one big blur. I've read extensively all my life and I can barely read.*
- *I'm writing . . .crowded page.*
  It's moving, it's mutating, it's everything in you. Ccc, H-U-R-C-H-F instead of five. B's instead of P's. P's instead of B's. There's a number of funny little things in my brain, and sometimes some do things and sometimes others do things.
  It's very frustrating to go to get something and it's not there, but it's there.
  I can often see things faster if they're moving.
- *And so if a bird flies across his vision, he's got it. He knows what that bird is. He can see it exactly as it was before, because it's somehow it's dragged his eye to it.*
  The glare when you're walking along, it's very, very bright.
- *And there's shadows and reflections or glistening puddles. Is it real? Is it solid ground? Is it something you're going to go down,*
- *going downstairs I can't see my feet.*
- *I always feel for the first step, so I can gauge the rhythm of the stairs.*
- *You do not know where to put your feet, so you get vertigo. It gives you vertigo.*
- *Well, it's like standing on the edge of something that you could just jump.*
  I can play all the notes, but not necessarily in the right order.
- *I can make a cup of tea, but if Graham talks to me in the middle of that, I will forget at what stage I was at.*
- *First of all, I've got to find a cup.*
  It’s almost as though he must be able to see it.
  I can see it, but I can't see where it is. I still couldn't see it.
- *Where? There. Where there's a real one and there's an image. I can't distinguish between them.*
- *You have to dismiss the whole image. Somehow, and then get it to reassemble the whole thing. And then the kettle might be there again.*
- *Like, your reading glasses are in the midst of a load of other things. You can't spot them very easily.*
- *The whole thing, you do see it rather like a Breughel painting or crowded, surreal.*
- *My fingers were like bananas.*
- *I can't use the phone properly.*
- *You can Remember the code for your cash point? But you couldn't work the machine to put them in the right order.*
- *Oh, yeah, I can see the computer and something will come up on the screen. If I press the wrong key, then I'm stuck.*

SC, chair I hope that gives you a flavour, a little bit of an insight into some of the experiences and uncertainties of living with this condition, which affects not eyesight, but brain sight. So, on that topic, with that as a bit of background and context, I'll let Charlie introduce our first speakers, Helena and David.

CH, co-chair

Helena and David are really creative people who I've got to know a over the last year or so. They're involved in lots of things, like singing. They were involved in the Rare Space Garden that I mentioned briefly, in a previous Wigmore Hall project, Out of the Ordinary. They've also spoken to me about going for a swim in the sea and also rewilding their garden, and we often talk about our dogs as well – all valuable topics of conversation. I wondered if you could start off just telling us a little about yourself and when you started making art, Helena.

Helena I probably started doing art when I was a child because my parents both painted. But then after being a child, it became a thing where, well, that's what they do, and I'm a teenager and I'm not going to do that. So I didn't do any art at that point.

David The interesting thing was that it was when Helena's parents had died - going back seven or eight years – I suspected that Helena could have painted because our sons are both very good, partly because they were taught by Helena's parents. I'm thinking, well, it's probably in there. but there's been not wanting to be inferior to your parents, I suppose, from Helena's point of view. After they died, Helena wanted to do some art.

Helena I studied art history, a lot of art history.

Visuo-spatial challenges

David You signed up for a course at the local college, where the artist taught drawing in a very conventional way – this was probably three or four years before we'd really understood that Helena was having visual problems. She had eye tests, glasses, but we had no idea that anything much was going on. You kept going for half a term, but they decided that as far as this art class was concerned, Helena couldn't draw, because already the PCA was giving her a distorted sense of space. That meant any attempt to try and be representational, learning to draw in the classic way just wasn't on. It wasn't there at all. It was deeply demoralizing, upsetting, wasn't it? It was very strange.

Helena But the interesting thing now I realize is that because one of the things that I have found from the beginning that's really strange, is the spatial stuff. I couldn't get into a car because of the spatial aspects of knowing which foot has to go here or there, not because I was going to drive, don't worry, but because it was just really complicated all of a sudden.

David Finding the door of the car became an impossibility and very bizarre situation with left and right. Helena would often not understand the left side of something – the car only had a right-hand side; and the right-hand side of the car only had a door was the driver's door. So whenever Helena approached a car, she would try and get in the driver's door. Really strange.

Helena Very odd and troubling situations as well.

CH Like the one with the original art class you went to as well which was really dismissive and terrible. I know now, having spoken to you quite recently, that you often refer to yourself as an artist, Helena.

Helena Yes, yes

CH, co-chair Would you like to give us a tour of some of your paintings, as you speak about that journey as well.

Helena Yes

WIGMORE HALL

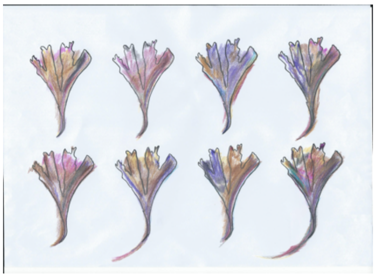
David Very early after Helena's diagnosis, (through RDS we got involved with Wigmore Hall, 'Out of the Ordinary' music project. It was all online during lockdown and rapidly became a mix of music. There were music students who were improvising in response to stories that people with PCA and other conditions were telling. We were in the immediate post-diagnosis, grief phase, where everything was very difficult. But it became something where it was Helena's session. Out of it came tasks for the next week and challenges to go and observe outdoors.

Colouring silhouettes of seaweed

One of the first things was we found a piece of seaweed on the beach that Helena was particularly fond of.

Helena I liked the shape of it.

David This was a silhouette of the seaweed, duplicated many times that Helena then coloured in different colours to respond to the joy of suddenly seeing that seaweed was really pretty.



Helena It was really pretty.

David We'd lived next to the sea for ages and never got there. That was one of the first things, wasn't it? **Helena** It was.

Expressing Anger through art

David There are some other examples on the Rare Space site where Helena has a page of some things which expressed how she was feeling. The angry tunnel and things like that.

Rare Space

"There were times early on when I was really cross and angry with everything, and I would make something and be able to say to David, "this is how I feel!""

Finding a local sight-loss arts group

But the really big thing was finding an arts group that's run out of one of our local sight loss charities, run by a couple of art therapists. Could you talk about what that's like?

Helena Yes, I was looking for a group and I knew that I wanted to be in a group rather than just doing the art by myself. And luckily, I think, though, I went to the local museum and said to them, Do you know anybody who is doing some art and I've got a visual impairment, so it has to be of a particular nature. And they said, ‘Yes, we know two people and we could give them a call.’ It was a combination of the two things together that got me into art.

Masking areas of artwork to help focus

CH, co-chair You've mentioned in the past making artwork. I hope you've got a few more that you can show us. As there are particular challenges with PCA for making things, I've heard you speak before about taping off areas of the canvas, so that you can focus on particular areas.

Creating texture

You spoke in a lovely way about having a particular painting you had made where the sound of it was particularly nice because you had made it out of plaster and you could tap it.

Helena Yes.

David This is a very abstract thing, but if you go in close, it's got a lot of texture.

Helena A lot of texture.

CH, co-chair It's lovely. How does it make you feel, Helena, when you're making this work?

Helena I really enjoyed it. I liked the feel of it. I really felt like it was mine.

I did it just after I'd been up to London to see the Summer Exhibition at the Royal Academy. It inspired me. I think that's one of the things about art as well, isn't it? - you can go somewhere, see something and it'll give you an idea.

Vibrant colours with PCA

David One of the first things that Helena did with the art group is actually behind her on the wall.

If you lean over to me a bit, they'll see it, which is very abstract and quite drippy. But it's great. It's just got so much vibrant colour. PCA may lose shape, but colour is still really important.

Growing confidence as artist of quality, in social artistic milieu

CH, co-chair I think that's it. That growing confidence I've seen in you, Helena, as well, through making this art as well you've also mentioned. Because you go to a regular group where you speak with other people and you're inspired by their work, they're inspired by yours. I often find that those groups are quite helpful. Does that resonate with you?

Helena Yeah, absolutely. I am really glad that I'm in a group.

David I can see that the real quality, the expertise of the therapists who work there to facilitate Helena to do the art, but to be there very gently doing things to make it work, to make it not go wrong, this masking off thing, it's quite tactile. I see them getting a hold of her hands and putting them on the paper and say, look, put your hand here and then work in this space, within this frame. This is what you're doing now.

But you always have the ideas, don't you? And you get to the end of one piece of work, then you're always thinking, what am I going to do next? Often, it's very intangible, just about a colour or something. I'm going to do something in whatever colour, or it might be something to do with the beach or something like that.

Rare Space Garden at the Chelsea Flower Show

We had quite a lot of inspiration from our involvement with the Chelsea Flower Show.

Helena We went a bit flower bonkers.

David That's a nice flowery one.

CH, co-chair I think you said you made that almost the day you came back from visiting Chelsea after the garden had been shown.

Imagining the fragrance

Helena I just wish I could have the smell.

CH, co-chair I think we're all getting a sense of the smell there. Such a beautiful painting. Thank you so much for sharing some of your work and talking us through how that process has been. it's just so great to see you talk about your art and I'm a big fan.

Helena Thank you. It's really good. I love it.

David It's clearly a massively important part of Helena's wellbeing to be involved with this kind of thing.

Community Choir member

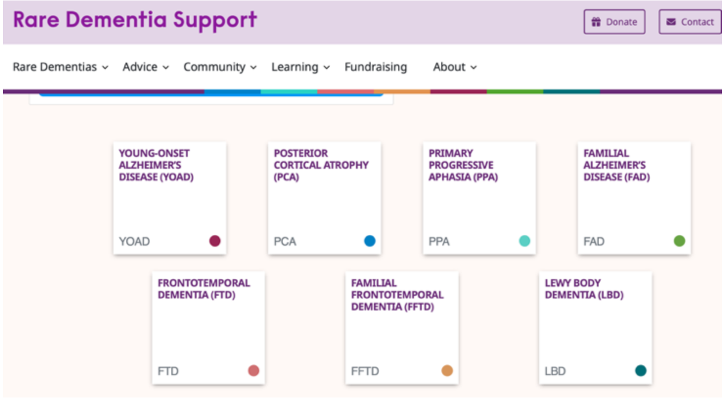
And she sings in a community choir. Not a dementia choir, just a local any ability group, and again, that expression is a key to dealing with these things. If you can't get out and do things

Helena I think doing things with other people.

CHAT **kate white** (Volunteer, Cambden Carers) So movingly represented - thank you.

SC, chair Thank you so much, Helena and David, for sharing that. I think you've been a fine advocate and I think we should all go a little bit flower bonkers or bonkers inspired by whatever we're engaging with at the moment, but that's great. Thank you. And I know you're staying on to join us in the Panel Discussion a little bit later on, so we shall hear some more soon.

Supporting Rare Dementias



Just before Charlie speaks with Chris and Andrea, I thought it would be helpful for me to mention that visual dementias are not the only types of conditions that we try to support through Rare Dementia Support, as you'll hear in a moment, much better from Chris and Andrea and via their work.

We also support people living with types of dementia which affect language.

- The broad category of conditions is called Primary Progressive Aphasias, or PPA, which really just means that language takes the prominent role earlier on and is a progressive change in those abilities.
- And there are at least three different types of language-led dementias, some, like Semantic dementias, which affect one's understanding and the type of memory that we have, not for day-to-day events, but for facts and knowledge about the world, including what words mean.
- Another type of PPA, Non-Fluent Progressive Aphasia, means that people understand perfectly well and know exactly the message they're trying to convey. But the fluency of their speech and their ability to use grammar and to articulate sounds and words in the way that they normally would have is progressively affected.
- Then a third type, which Chris and Andrea know much more about than me, called the Logopenic variant of Primary Progressive Aphasia, where things like word-finding, repetition and hesitancy when creating sentences ,are issues that come to the fore earlier on.

That's a bit of background, but the most important thing is not, as we've said, what disease the person has, but the person living with that condition. That's what Charlie and Chris and Andrea will be talking about a little bit in the next few minutes.

CH Fantastic. Thanks, Seb, and welcome, Chris and Andrea. Thanks so much for being with us today. Again, more very creative people who I've been getting to know over the last couple of years.

Chris and Andrea Chadburn

A very quick intro to say that you have interests in drawing and painting, poetry, cooking together, gardening and playing football with the grandkids - I know Chris is a big Burnley FC fan - and visiting museums.

You told me that this week you've been to see the Turner Prize at the Towner Gallery in Eastbourne, which is lovely to hear. You've been going out and about as well. Chris, would you like to introduce yourself.

Chris Sure. I live in Sussex. Andrea is my wife. 50 years - 50 years last year. It's now pretty much three years since I was diagnosed with Logopenic Aphasia - very debilitating. I know what I want to see, to say, but I can't say them. I have good medication, good speech therapy and both help. And I feel that from the three years I'm pretty much, that's where I still am, which is . . .

Andrea It is quite good. And it's having a sentence in your head. And he knows what he wants to say, but he hesitates, and he can't get the word out. It can be quite frustrating.

CH, co-chair That must be so frustrating. Also in social situations, we live in such a fast-paced world now, people aren't great at giving people space and time. That must be so difficult. Could you tell us more about that and whether you feel creativity helps at all.

Chris Well, I'm at the point now that I know what I can do and I know what I can't do. When I can't do things, I just walk along. I just want to keep going on until I can't do anything. We have a good life.

Enjoying art

Various things we enjoy, including art, but I don't do as much art as Helena does, by a long way. Drawing. painting, I always liked it at school, but I didn't go painting or drawing for a very long time. I was just thinking, it was when we were in Hungary and we had our boys there, and we had a day that we all had a painting, and it was really good. Then I never did anything for about thirty years. That was just because of work, we've got children and a lot of things to do, but it was when . . .

Andrea Lockdown.

Chris So when lockdown was there, we got a lot of stuff, painting, enjoying, and it seemed that we were quite good.

Starting to Paint

Andrea It was always something that we quite enjoyed doing, both of us, and drew with the children. We like going to art galleries, but it's a little bit like a lot of hobbies, you have to invest a lot of time in it. Then Lockdown brought that opportunity where we had hours in the day where we had not a lot to do. So we both started painting, and we discovered how much we enjoyed it. We discovered that we were not too bad at it, so we've carried on. We don't do as much as we did in Lockdown, but we still draw, we still paint. We're not good enough – not as good as Helena – to put a picture on the wall.

<u>Creating cards for friends</u>

We decided that rather than just keep them in a drawer, that we would draw pictures for our friends and our relatives. We've created birthday cards and anniversary cards, Christmas cards. Do you want to say a bit more about that, Chris? Do you want to show the latest one that you've done?

Chris The last thing I did was at the football ground.

Andrea This one has yet to be made into a card. Chris, do you want to talk about it?

Chris That's Brentford Football Club ground. I go there quite often, and I've got a friend who comes with me to the matches and sometime I don't know when he'll get a birthday card from me.

Andrea I think it's September.

Chris I've got another one which was 1997.

Andrea Only black and white, because we send the original ones to the recipients. But that was. That was West Ham.

Charlie's got a few pictures that Chris has done, but we don't keep the originals. We send them, make them into cards and send them to our friends. So the Brentford one, the guy at the front is Chris's friend, who he goes to football with. So he will enjoy receiving that in September.

Chris He doesn't know.

Andrea But we do other creative things.

Chris Well, I was thinking, we don't do art very much, really.

Andrea Normally in the winter we do more.

Chris But we do a lot of walking. Not when it's.

CH, chair And poetry as well. You had mentioned poetry as well. You had mentioned which poetry I think a lot of people might find counterintuitive for people living in this situation, but I love hearing you talk about poetry.

Poetry

Chris OK, the poetry. I'd always thought I should really get into poetry, and I had loads of poems that I'd got from charity shops. I must have had fifteen or twenty, but I never really did it until . . .. **Andrea** It was a speech therapist

Chris Yes, it was a speech therapist. The therapist told me about a patient who read the newspaper out loud every day. I thought this was too depressing. So I started reading Andrea a poem every day. And I do it every day, every morning.

Andrea We find that it helps his diction and his speech, and often we don't understand the poems, and so it creates a discussion which, again, helps Chris to have a conversation. He's got a very short poem that he's going to read. Which one is it?

Chris It's a funny one.

Bloody men

Bloody men are like bloody buses.
You wait for about a year,
And as soon as one approaches your stop,
Two or three others appear.

You look at them,flashing their indicators,
Offering you a ride.
You're trying to read the destinations.
You haven't much time to decide.

If you make a mistake, there is no turning back.
Jump off and you'll stand there and gaze
While the cars and the taxis and lorries go by.
And the minutes, the hours, the days. That's Wendy Cope..

CH, co-chair Beautiful.

Chris I think it's funny. **CH, co-chair** I love that. And very well read as well.

Chris I can read perfectly well, but it's getting what's in there.

CH, co-chair Thank you so much. It's really lovely to speak to you again and thanks so much for joining us today and look forward to hearing some more. I've seen lots of lovely comments coming in through the chat box as well. There's lots of interest in that = and there'll be more to talk about in the Panel Discussion, no doubt.

Chris Ok, that's good.

CHAT Anna Twells (Arts facilitator, Creative Minds) Such amazing art!! I love them all! Love the poem idea!
Jemma Saunders (Dementia Advisor, Andover Mind) They seem very Lowry inspired Chris - they are great
Bisakha Sarker MBE (Creative dance practitioner, founder Chaturangan Indian Dance) Much more than what I expected to learn. It's so entertaining.

SC, chair Thanks, Chris, Andrea, so much, really kind of you. Wonderful ideas there.

Tony T, Chief Executive, Artistic Director Rebecca Goldstone, Co-Director and Producer, Sweet Patootee Arts.

SC, chair So next we're going to be turning to a short conversation between Charlie, Tony and Rebecca. Lovely to see you. Thank you for coming.

Accessing appropriate support for rare dementias

A little bit of background: RDS, like many, if not hopefully, all organizations, is really conscious of how difficult sometimes it is for people with rarer dementias or other potential users of those support services to reach the services in the first place. That's partly because of the rarity of these diagnoses and people's general lack of familiarity, both in the public and the professional realm with some of these conditions, but also because of other factors that might limit people's access and inclusion in services, people's ethnicity, their socio-economic position, where they live, different types of stigma and misconceptions, particularly around what dementia is and assumptions people have made about them before they ever get their voice heard in the conversation.

Putting lived experience, inclusivity, front and centre

We're very interested in different approaches to work around equality, diversity and inclusion, as I hope is clear from Charlie's wonderful conversations so far, is very much wanting to put the lived experience and the voices of people who actually really know what it's like to live with these conditions front and centre. So, for example, with a lot of our outreach work, very generous members of our RDS community, whether with a diagnosis themselves or caring for someone who has, are out in the community, faith groups, community groups, professional organizations right around the country, essentially trying to get people to ask a really basic question:

Awareness of dementia type

Encourage them to say every time you hear the word ‘dementia’, to ask yourself, ‘What type?’ Just to try and raise and deepen. We've got very broad awareness of dementia, but now we need deeper awareness and understanding of how these different conditions can materially emotionally, spiritually, and in other ways socially affect people in so many different ways.

Rare Dementia Support partnership with Sweet Patootee Arts

It's with that interest, that set of values, that it's been really great to hear about the relationship Charlie has been building with Tony and Rebecca and their organization Sweet Patootee Arts over the last couple of years and through this partnership to understand how knowledge can be exchanged between different community groups and art venues, football clubs and dementia networks. And you guys will tell us all about learning from the experience of people in the black British Caribbean community and people with that heritage.

CH, co-chair Tony and Bec are creators of incredible heritage work that have been working this area for a long time. They're really experienced in working in the community and connecting with people in organizations. You're currently touring a film called *Turning Point*, which is such an amazing film. It's four short films, in fact, inspired by histories of black Caribbean experience after the First World War. Could tell us a bit more about that project and how it connects with your heritage work.

Rebecca We first started working together, working primarily on oral testimony, so a lot of work doing historical research, and because of Tony's Caribbean background, we ended up doing some TV museum interpretation. It was all factual work and connection with the community because of the type of stories that we wanted to tell. We were looking at that, Britain's colonial heritage. That's the context that we've built on since *Turning Point*. We wanted to revisit our art background.

Four stories set in Jamaica and Barbados to show in a gallery – and on a laptop

Tony had been writing, more dramatic writing. He started to use the information that people had told us about that period, the First World War and after. The *Turning Point* stories are set in Jamaica and Barbados in the 1920s, and an emergence of more Black Pride. There are four stories, two women, two men - some quite serious, also comedy and melodrama. Each one is ten minutes long, a theatrical performer giving a monologue, that performer responding to voices. We also wanted visual, quite immersive to work well in a gallery situation, where it could play on a loop, people could come and go. The sound would be important, but the visuals and the story. It has flexibility. It can be watched on a laptop as well.

Importance of sounds, hearing dialects, idioms evoking memory

The sound is important because there are lots of aspects, the Caribbean, the Jamaican and Barbados dialect, so we have subtitles. But for people from Caribbean communities, they fed back to us, actually being able to hear dialects and idioms and their connections with that, but also the sounds as well, whether it's birds or wind, there are lots of things that are very evocative. As Helena was saying about going to the Summer Exhibition and seeing other things, how it can spark ideas for yourself to be creative. Our idea is for people to be able to go and enjoy it as it is, but also, hopefully, going forward, we'll actually be able to work with partners to have workshops where people can watch *Turning Point*, or just one story from *Turning Point* and use that as a catalyst for their own creativity.

CH, co-chair You approached us because our interest is around rare dementias, and not just rare dementias, but more broadly as well. Some of the resources and services that are available for people from minoritized groups aren't particularly appropriate, and they don't serve the needs of these different communities. So another way that art can be powerful is that through artwork,such as a *Turning Point* film, that can be used as part of the resource toolkit that we might be able to share and connect with people.

The difference between someone like myself going into a community centre and talking about PCA or PPA, is not a very useful start to the conversation. Whereas entering into a situation where we're able to show aspects of your film, connect with people's heritage, really important parts of people's history, and then introduce the idea that every community centre that we've been to with this, people always say, ‘Someone in our group's got challenges with language or challenges with vision.’ It's building that trust and those connections through that work, it's so important.

Rare Dementia Support Connecting with Heritage

SC, chair Tony and Rebecca, one of the things that's been so helpful for us as Rare Dementia Support in our learning is that our premise is often that people feel quite isolated because they've been given a rare dementia diagnosis and they've never met anyone else in the similar situation. So, our role is to connect people, give them, help them find a sense of community. What we've learned so much about from your work is that the other pattern is also very much true, that if you can reach people by connecting them with a community they're already part of and keeping them connected, then out of that relationship, we might then meet people with these different forms of dementia where that supports, as Charlie says, not putting the diagnosis first, but putting the person first and building from an existing relationship. I wonder how easy or difficult you found it to work in that way, because it's certainly the opposite of our practice.

Tony T I think that it would be a complete lie to say that it was easy because we have to work with support networks. All of those things had to be put in place. On the other hand, ours has been a participatory practice for over twenty years, developing projects, identifying contributors, developing support networks, when we work with contributors, developing story and so on. *Turning Point* is in many ways an evolution of lessons we've learned. There are different examples. For example, the amazing day when we needed to know whether the humour was working.

Hackney Caribbean Elders,[1] We went to the lovely day centre, not far away from where we're based in Islington London, at Hackney Caribbean Elders. They just dropped us in the deep end. They said, *It's going to be lunch in twenty minutes, half an hour. Everyone is here at the moment in the day room, have at it.* We'd recorded little bits of our rehearsals on our phones and downloaded that onto the

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[1] For Hackney Caribbean Elders, see Cultural Diversity in Arts for Brain Health Webinar, July 2022, pp.18 ff.

computer, played back the computer to groups of people, some of whom we didn't know were living with dementias of one form or another. But there were people who came into the moment in a very big way. So much so that the support worker you met, Charlie, they were more than us because we didn't go in there with a methodology and an intent to try and provoke work with these people. It really came by accident. But we had a sense that there was the potential and the need to be sensitive to the ways we needed to enable people who might be living with dementias to work with us.

The upshot of our session at the Hackney Caribbean Elders from those people who worked with us on the sessions about the humour, that the humour did work, got thumbs up. They gave us fantastic crit about other aspects of the stories. They also participated in building the sound design that Bec was talking about they recorded for us as well. They all came into the moment. And the centre manager and the other staff saw ways that they could be developing work with us. We're going to be following that up. I believe that they want to follow that up with you as well, Charlie, as well. So these things are doable and possible, but the structures had to be put in place in order for them to work. Otherwise, it's not sustainable. You just make a flash and then it goes.

SC, chair Absolutely, thank you, Tony. That's really helpful. That theme of sustainability is one we'll come back to in the conversation in a minute. If you don't mind staying on screen, I'm just going to bring Monica Boulton in to join us.

Monica, thanks so much for being with us today. Could you briefly tell everybody about yourself and your role. And in particular, several people in the conversation so far have mentioned Social Prescribing. So maybe you could give us your personal definition of what that means to you.

Monica Boulton, National Academy for Social Prescribing

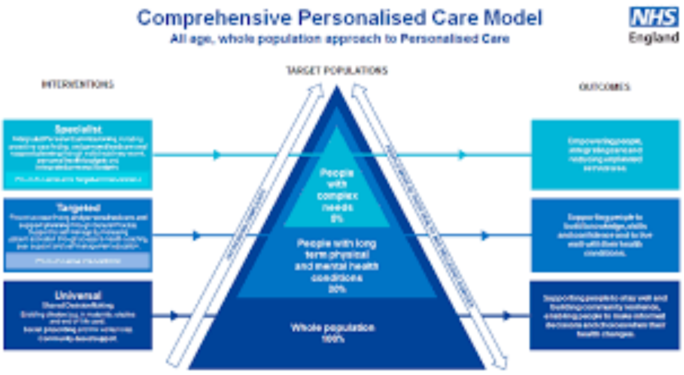
Thank you. It's really great to be here. I'm already feeling inspired, so looking forward to continuing this conversation.

I work for the National Academy for Social Prescribing (NASP), as their Healthcare Integration Lead. I've had a background in an interest in Creative Health, particularly around music supporting people with dementia.

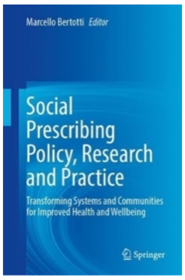
I think the essence of Social Prescribing (SP) has already been beautifully captured throughout much of the conversation that we've been having. But just to put my spin on it, I SP is largely a holistic and very person-centred and community-based approach to health and wellbeing and bridges the gap between clinical and non-clinical support services.

Connecting people to local activities, services and local community support

The essence of it is that it's a way of connecting people to services activities, support their local community, essentially that all have benefits and aid improvements in people's health and wellbeing. SP has, and similar approaches as well, have been practiced in the NHS



for years and years. But the NHS Long Term Plan 2019 marked a real shift because SP was incorporated into the Comprehensive Model of Personalized Care. Since then, around 3,500 SP link workers have been recruited directly into the NHS with commitment to recruit up to 9.000 by 2032 in the NHS Long-Term Workforce Plan and the SP movement has been explored, recognized, adopted all over the world, whilst continuing to gather momentum within research, academia.



In fact, Marcelo Barottti's new resource *Social Prescribing Policy, Research and Practice: Transforming Systems and Communities for Improved Health and Wellbeing* demonstrates the multitude of ways in which patients can connect to varying SP services in across the world.

SC, chair That's brilliant. But it's really affirming to hear that many of the things you've heard already in the Conversation share the essence of SP for those of us, just to make things a bit more practical for those of us either with a lived experience or professional background who don't feel they've explicitly or knowingly connected with SP practice before. I wonder if you could just say about how that happens and also what people might expect from a conversation with one of the link workers that you refer to.

Monica I think it's probably important to highlight here that SP is not intended to ever replace or undermine medicine, but to complement and work alongside it. The main ethos of SP, as I say, is encouraging it to be person-centred and all built around this What Matters to Me conversation.

Locating and referral to local SP link worker

In England, SP link workers are predominantly embedded within primary care network. So your GP practice, meaning that healthcare professionals or other professionals in that Primary Care Network (PCN) who have identified perhaps a psychosocial issue, can make direct referrals into that SP service. There are some SP services that enable referrals from other professionals, such as fire service, social services care coordinators, people like that. But the first thing that I would suggest, if you're looking to find your local SP service, whether you're somebody in need of support or perhaps a creative organization looking to connect, would be to look on your GP or PCN website – hopefully, SP details are logged there.

Link worker identifies What Matters Most to the person - needs, skills, interests, aspirations

Once you've been referred into SP, to the link worker - in contrast to the GP's ten-minute appointment - the link worker will spend up to an hour, sometimes more, using their expert skills and techniques, such as motivational interviewing, behaviour change techniques to get to really know what matters to that individual, what their interests are, what priorities they might have, what brings them that real sense of purpose and aspects of their wellbeing that they might want to improve.

Linking and empowering person to engage with chosen creative and cultural activity

Then through the connections that they've made with their local community, they can identify the services that are available to that person – including creative and cultural activities – and explore the barriers that there are to accessing those groups and services, and then be the bridge, if you like, empowering that person to engage with that onward referral.

The involvement can be anything from two weeks to six months. It's very client led and of course, health and wellbeing is ongoing and changeable, as we all know. And so sometimes link workers might see somebody more than once over a six-month period, or even longer.

Social prescribing pre- and post-diagnosis of dementia

Bringing it back to the dementia side of things. It's important to recognize that SP can be relevant at any stage of a condition, including dementia. So it could be pre diagnosis and also not just relevant for the patient, the person, I like to say, rather than patient, but also for the caregivers, the wider family too, as they navigate that world pre -and post-diagnosis.

SC, chair That's fantastic. Really brief and comprehensive summary. Thank you.

Monica Boulton happy to be contacted for further conversation: monica.boulton@nasp.info
Bisakha Sarker Veronica you have found a wonderful new format of webinar
Veronica: Thanks to Seb and Charlie – and shortly, Eloisa and Cristian – and artist members!

PANEL DISCUSSION

As we welcome Helena and David and Chris, Andrea back onto the screen for a few questions between us, do please feel free to ask questions of each other.

I just wanted to pick up on that final point you made, Monica, about the different stages which links in with Tony's point. I think about continuity as well, because there's continuity for the organizations, fantastic organizations like Sweet Patootee who are offering fantastic cultural opportunities, and the different arts organizations that Helena and David and Chris and Andrea were talking about. But there's also continuity for the person living with the condition or caring for and about that person as things change, because sadly, these are progressive conditions. I remember David mentioning that in describing one of the activities that they'd been part of, I think with Wigmore Hall, you said that was just at the stage where you're in that immediate post-diagnostic grief phase. So presumably, the link workers in directing people towards opportunities, but also Tony and Bec, you and Charlie and others, in responding to the people you're meeting, have to be operating, you have to be very nimble and on your toes in responding to people, not just different people and not just different diseases, but different people with different diseases at different stages or facing different challenges. How does that look? The link worker world sounds like a wonderful but very daunting role.

Need to embed SP referral at the onset of symptoms [2]

Monica Yes. Link workers cover a multitude of issues through their work and come from a variety of backgrounds with varied expertise. It is really about getting to know that local community and the time that they've got to get to know the person. I think that it's a really exciting way of embedding creativity at the start of somebody's journey. So, once symptoms first appear and it can contribute, that conversation to be right at the very beginning of somebody's journey. I think it would be great to see a world where referrals to SP become the norm as discussions are had around potentially life-changing conditions. Because then if it's embedded at that early stage, it's then more likely to be incorporated in the later stages as well, also for the family. I think it just starts that conversation of what non-medical interventions can also do. By embedding with that community, you've then got that more sustained care.

Need for sustainable arts prescription programmes

But obviously that then is reliant on the sustainability of organisations, which Tony touched on. That's why it's really important that SP is not just seen as the isolation of the role and why it really helps to bridge that gap between the community and healthcare to make sure that those two things are in sync with one another. Hopefully that answers your question.

CHAT: Veronica NASP's Thriving Communities programme centred around multidisciplinary partnerships that enable sustainable programmes - featured in our A.R.T.S. for Brain Health Social Prescribing report

SC, chair Yes, very comprehensive. I don't know if anyone else has any comments on that. So about either how you find the right thing at the right time, or, for Tony and Charlie, how you adapt to the different needs people are facing at different stages in their condition.

Tony T, Sweet Patootee Arts For me, in practical terms, it's about building trust, really, and relationships. We've essentially permanently got relationships with people who are gatekeepers in communities and also family and community social services. So some relationships they call, but we have a basic function of maintaining them all the time, and that's a huge drain on resources. But in terms of project delivery, it's because we have those relationships, we have the opportunities of being well informed. When we take an opportunity somewhere, we're not coming with an expectation that one strategy, one approach will fit everybody. It does become person-centred and the needs are understood and the sessions are structured basically, and then they become appropriate. But it's a crucial thing. There's no easy solution to the demands that it makes on us as an organization. It's the way that we choose to work, but it does take an awful lot of our time to maintain those relationships. On the other hand, the proof of the pudding, I think, is in the enjoyment of those sessions, because we all enjoy them. We all do, but also, the work that comes out of it

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[2] *A.R.T.S. for Brain Health: Social Prescribing as Peri-Diagnostic Practice for Dementia* (2021) calls for this specific amendment to NICE guideline [NG97] Dementia: assessment, management and support for people living with dementia and their carers. June 2018.

and then the opportunities to share the work with the public and the feedback that comes as well. Everybody seems to be having a good time and it's a model that really does work.

SC, chair That good time really seemed echoed in Helena, David and Chris, Andrea, and in your experiences of the groups and opportunities and activities you've been part of. Tony just there was stressing the importance of trust and also the challenge of sustainability, of maintaining those relationships. I was curious to know, in terms of trust and sustainability, how easy or difficult do you found it? Because presumably some of the activities and relationships you've built up have been for a fixed time, activities that have begun and had an end date. Is that right? And how does it feel when things come to an end or opportunities can't continue.

David Well, I think things like In the early days in lockdown, when there wasn't much going on, then there was a sense of loss at the end of something that had been good. And early on there was some Queen Square research into small groups that Rare Dementia Support were doing, that Helena was involved in. That was another thing which was a real high point of the week to have that contact and then it ends and it is a bit devastating. That was all exacerbated by it being in lockdown and there not being much else.

Social connection, trust, feeling safe

Now Helena's got a lot on. She just recently stopped volunteering as a befriender at the local food bank as another connection. I think all the things that in the end have worked for you are where you've found that connection with the people and the trust of the people and feeling safe. I mean, in the end, that's the key, isn't it? It's very difficult. If you were going into a situation where you were not feeling that the other people that you were with were looking out for you,

Sing Well

The choir works really well because such an embracing group of people who've just got lots of time and lots of willingness to accept everybody as they are and to make it work. That's the thing. I mean, it's a lovely set up, really. The lady who runs it - it's her calling almost, to do this. She was involved in schools and things previously, but I think that creating a community that is not just about singing, it's about the community as well, and to let anybody be part of that.

Helena It's called Sing Well.

Community singing less pressured that a chamber choir

David I sing in a chamber choir, which tries to do everything very properly, and it's all quite high pressure. The difference in the wellbeing that we get from our different choral activities is quite stark. I get lots of wellbeing from the music. For Helena singing with people is great, but there's so much more time in the community choir for it to be more than just music. That's a key thing.

And I think the same at your art group as well. You' talk about all sorts of things, and it's a very wide, general, safe environment for.

Helena Talking about life, the world and everything.

On Value of Dance

SC, chair We haven't talked about dance today, but people often talk about dance as being like the holy trinity. Its cognitive. You have to think about it. It's physical, but critically, it's also social as well. Rebecca was talking powerfully about the different components, these very immersive experiences, not just the vision, but the stories and the sound. That's something that we notice being offers that are particularly well received by broader members of our RDS community because people will have different access needs. Those really rich experiences mean that you have that element of something for everyone.

CHAT: VFG adds: Lyons S. et al, 2018. What research evidence is there that dance movement therapy improves the health and wellbeing of older adults with dementia? A systematic review and descriptive narrative summary, *The Arts in Psychotherapy.*

SP referral throughout healthcare journey for sustainable (arts) prescription programming

Monica, SP Can I just come in on the point? And I don't think it's just relative to SP but Creative Health more broadly. It is that we've still got quite a long way to go in terms of not boxing who fits the mould for who these creative activities can benefit. It goes right through the whole spectrum of someone's healthcare journey. Appreciation of that can perhaps lead to more sustainability in some of these things, which are often quite short term. We see it as relevant to and just as important in somebody's healthcare journey as the medicine itself. Therefore it needs to be sustained and more widely available. So I think there's more learning that we can do on those benefits to then encourage that sustainability - culture change.

CHAT

Jane Ward 16:44 I agree with Monica, we need a better system to enable linking between social prescribers and the organisations offering groups

Monica Boulton, **NASP** 16:42 On the topic of funding, we recently announced our Power of Music fund in collaboration with Universal Music, the Utley Foundation, Music for Dementia and others which will support grass routes organisations who provide opportunities for those with dementia to connect with music. Part of this project includes a "Centre of Excellence" which is a larger funded project which will hopefully provide valuable insight on the topic of integration with health as well as sustainability of funding. More info here: https://socialprescribingacademy.org.uk/the-power-of-music/the-power-of-music-fund/

CH, co-chair In relation to that sustainability point, Seb has been working very hard and others at RDS about bringing about the world's first RDS centre. So much of what we've been thinking about here today has been around how we can maintain and create a cultural space for people as well. Because I think when people are coming into clinic and doing those other things, you also want a space where people feel welcome and at home. As you know, London is a very busy place to come to. So lots of what we're thinking about is around having a base where we can express all this from our perspective. It's always been a question with our work, that you want to help everybody; and we have so many thousands of members, but the work of other groups, as we've heard today, is so important for people to connect within their own community. We can't run every group in every community, and so it's really important that people are talking to each other and different organizations are talking to each other.

SC, chair Completely agree, Charlie. And that's where those relationships you talk about are so complementary. I know that we've met lots of different people through our relationship with Tony and Bec as well around the UK, because we're trying to be a service for everyone.

CHAT
Jane Ward It's wonderful to hear about the provision of support over time by through the rare dementia support network. Continuity is of the essence being known and understood over time is crucial for us all but particularly when we are feeling vulnerable and needing support. The NICE guidelines do say there should be one point of contact over the lifetime of people living with dementia. I think there is a need for relationship over time attachment theory has a lot to say on our need for others. The finding of opportunities is so fragmented. I think fragmentation is very costly as not enough people attend than the funding is withdrawn. Things need time to grow and develop. Completely agree Kate. Huge issue for third sector is that we get funding for projects - but then, even if they are really successful, it can be tough to get continuing funding. We can spend a lot of time and effort trying to make enough changes to the project so it appears to be a new project so we can get funding for a 'new project'

Tim O'Brien 16:25 Question for Monica Bouton: Monica, while link workers have the opportunity to encourage people to try different creative activities to improve their wellbeing, how do they find appropriate activities? Is anything more needed to bridge the gap to providers that is not there at present? And are there enough providers out there? Is funding an issue?
Bisakha Sarker 16:26 There is definitely a need to train artists to deliver the work. It should become a part of art education
Veronica, Arts 4 Dementia 16:29 A4D provides early-stage dementia training for arts facilitiors
Tim OBrien 16:30 ...and A4D has been involved with Central St Martins running a programme with students there. We would love to be doing the same thing with drama, music and dance students!
Anne Stegmann Arts Therapists are perfectly placed to work in theses settings - art, music, dance therapists
Bisakha Sarker 16:30 Music to my ears
Anne Stegmann 16:33 Many Art Therapists work in museums and galleries

SC , chair One quick question that came in that Chris and Andrea may have a view on, but also a question for you, Monica, was about how easy it is to find activities. So the notion of a conversation with a link might be very encouraging and empowering, but that actual joining up. And the question from Tim O.Brien was about whether there's anything more needed to bridge the gap to providers that's not there at present. Just before you answer that, Monica, I just wanted to ask Chris and Andrea how easy or difficult you'd found it to find the kind of opportunities that you were talking about with Charlie earlier.

<u>Difficulty of large groups with Logopenic variant PPA</u>

Andrea Well, very difficult, really. It's hard work because of Chris's specific type of PPA. Being in groups of people is very difficult. Even on our social network, we stopped mixing with large groups of people. We tend to go out to dinner with just four of us rather than six or eight of us, because the more people there are around, then the more difficult it is for Chris to feel part of that organization. It's the same with going anywhere, really, whether it's an art group or any group activity because of that particular aphasia, then it's really difficult for him to become and feel part of a group.

<u>West Sussex PPA group</u>

We've recently set up a West Sussex PPA group. This has been done through UCL. We've got our second meeting next week. On our agenda is going to be: How can we make everybody with specific types of PPA to be part of a community that is going to work for them? At the moment, I think it's very difficult, which is why Chris enjoys doing art and poetry, walking, cooking. It's things that he can do on his own without having to talk, because that's his difficulty. But there must be a gap somewhere that we can fill.

SC, chair Thank you. That's really helpful. So, Monica, if it's okay to just come to you the final word.

Monica Yeah, I've read through the question in the chat, and I used to be a link worker, so remember the difficulties of there constantly being gaps out there in terms of provision and what's available. The simple answer is no, there's not enough funding, there are not enough groups out there.

Call for Intersectoral infrastructure– and more sustainable arts prescription programmes

Link workers have to work incredibly closely with the voluntary sector, and I think there is a real shift of healthcare and voluntary sector and local authorities working closely, more closely together. But I think we've still got a really long way to go, and I think that's why it's useful to see SP beyond the link worker role. The link worker role is at the heart of it, but actually in the context of a system and what is the infrastructure that's needed to actually enable that system to work smoothly? There's a lot more to say on that. But I think one thing to highlight is the data that can potentially be drawn down through the people that SP are seeing and what the needs actually are, rather than the reason why they're referred, can go a long way to then evidencing what's needed and then could hopefully bring down some funding. That's the blue sky world thinking, I guess. But that's the work that we're developing at NASP and we've got offers for integrated care systems (ICS) and PCNs to support that way of thinking a little bit more and really work in that very integrated way. So short answer is no, there's not enough, but I think we're on the journey to enabling a better, richer provision.[3]

SC, chair Great. Well, thank you so much for summarizing that. And let's hope in those ongoing conversations it can be not just, as you say, about fixing the funding gap, but also about seeing how things like what Tony mentioned, about trust being embedded at the heart of those systems and sustainable relationships. That'd be great to see over the next few years. Huge, huge thank you again to Helena, to David, to Chris, to Andrea, to Tony, to Rebecca, to Monica, and also very much so to Charlie for being such a big part of The Conversation this afternoon. We are incredibly grateful to you all. And I know if the audience were able to, they would be whooping, clapping, hollering and expressing their appreciation of all your contributions. Very much so. Thank you so much for your time.

Now we're going to hear from our wonderful Italian colleagues at Novilunio in Padua, Christian and Eloisa, and Frank and Fanny and Titzano. I shall now handover to Eloisa and Cristian to chair the rest of the session. I wonder whether you could introduce yourselves and say a little bit about your practice in Padua. It would be lovely to hear about that.

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[3] Since publication of *A.R.T.S. for Brain Health: Social Prescribing as Peri-Diagnostic Practice for Dementia* (2021), a proposal three-year Arts for Brain Health longitudinal study with UCL East has been agreed subject to funding.

Our Novilunio group photographed at Chioggia. (seaside town south of Venice)

Eloisa Stella, President, and Cristian Leorin, Co-Founder and Vice-President of Novilunio, of Padua, Italy, converse with rare dementia members, Tiziano and Francesco:

Eloisa Stella, President of Novilunio, Padua, Italy

We are a non-profit organization based in Padua, 23 miles west of Venice, in northern Italy. Novilunio, founded in 2014, is dedicated to inspiring a culture of positive change. This year we celebrate our tenth anniversary. From the very beginning, we have promoted the voices and perspectives of people living with dementia because we understood that most of the stigma and the prejudice that is around this condition is inked to the fact that people living with dementia, especially in Italy, are quite invisible - nobody sees them. We do our best to promote their point of view and to enable them to live a life as beautiful and full as possible. So, we organize peer to peer groups, both online and on site we also have a group for people living with communication impairments

Our group is part of a community working on activities, mostly associated with peer-to-peer support, which is core activity for most of whatever we design together with people living with dementia and their families. We organise peer-to-peer groups, both online and onsite and we have a group for people living with communication impairments.

Last year we started to organize activities focusing on social tourism, arts and culture, and social participation in order to give the opportunity not only to observe the beauty around us, but also to reappropriate our community. We shall be discussing this with Tiziano.

The right to a meaningful life, whatever our diagnosis - improving digital literacy

To fight against the invisibility that is common here in Italy for people living with dementia. we invest a lot of energies in advocacy, both inside our association. We also train other organizations here in Italy to take up advocacy for people living with dementia. Because we know that it is the way to promote their rights and point of view. Cristian also organizes courses and training opportunities to improve digital literacy for people living with dementia. He involves family caregivers so that they can work together and people living with dementia can keep working using their phones, their smartphones, Alexa and whatever digital technology is available, to enable them to maintain their full autonomy for as long as possible. And, of course, we have a helpline for people with dementia and their families.

I collected a few pictures of our tours last year. These places are mostly based in Padua, so we have Palazzo Bo, where Galileo Galilei used to teach. We went to see an exhibition of Frida Khalo, Giotto's frescoes in the Scrovegni Chapel. We went to the tBotanical. Garden, a World Heritage Site founded in 1545.

Eloisa introduces

Tiziano Tracanzan

Tiziano used to be a biker. He lives in Grantorto, a small village near Padua. He was a sales manager, and used to take his bike all over Italy and abroad. Tiziano is part of our peer support group, actually, two peer support groups here in Padua. He was diagnosed with YAD when he was 62 years old and has long known about Alzheimer's because he was the primary caregiver for his mother.

As advocate for Novilunio

Tiziano does a lot of things for us. He's an advocate. We involve him in our training for professionals, so that these professionals who work in nursing homes or in the community, have the opportunity to talk with the person with dementia, like a peer, for a better understanding of their needs or their points of view, which they usually take for granted that they know everything – that's rarely the case because we're all so different. We asked Tiziano to talk with us today because he was part of our Art and Culture group. I asked him to tell us about his perspective, how he lived that experience.

Eloisa asks *Allora, Tiziano,* ci puuo parlare di che cosa e stato per te le esperiensi di veder un po le musei *a Chioggia.*

Tiziano *Per me e una cosa molto molto buona perche mi piace l'arte … vedere queste a fatto prima elodi*

Eloisa translates Tiziano's replies He has loved the activities because he loves arts and he had the opportunity to see beautiful arts venues in the city. There were particular places

Tiziano *Quello di cui abbiamo parlato prima sono le cose piu belle che abbiamo visto, ma quello che mi piace vedere che è attraverso gli altri . . . le persone con noi, queste viaggioano se vedi che quando vci esauriamo fuori, vedi questi colori, queste belleze. E la cosa molto molto bella quando ci svendiamo vedere cose bellissime. E questo è tutto quello che c'è da sorridere sul viso. Sono Felice*

He adds, *I actually like all* the activities, the cultural visits. He explained earlier how he especially liked the Scrovengi Chapel and the Botanical Garden and, of course, Palazzo Bo.

Eloisa asks *Tiziano, quindi ti piace vedere le persone che godono*

Tiziano *Quando facciamo l'uscite fuori la citta, quello, per esempio, andare alla piccola Venezia.*

Enjoying cultural activities together in the community

He also says that the part of these visits that he likes the most is seeing the faces of people living with dementia and the families – happy. He enjoys seeing them smiling and happy, and enjoying a good time together with our community. That's the best part of the experience.

Eloisa Every time we meet, every time we go for a visit, at the end we also include a time to have some food. Of course, we're Italian! - the stereotype is very real. A good time with a glass of wine or a coffee or some pasta.

Visiting Chioggia (See our headline picture on page 31)

At the end of the first part of the programme, which was at the beginning of July last year, we went to Chioggia, which is a very small village near Venice - they call it a small Venice because it looks similar, but is a little bit more rundown. It's basically, the underdog of Venice. But we had a fantastic time together because there was the sun and the sea and of course, we ate a lot of fish and fried fish and everything else. It was really good.
Thank you. *Graze Tiziano.*

CHAT
Veronica, Arts 4 Dementia: The charm of these weekly gatherings is that participants choose together on the day which museum, gallery or site of interest they wish to visit.
Claire Street Grazie mille Tiziano
Tim OBrien Grazie Mille Tiziano. Buona fortuna per il futuro.
Veronica Tiziano you are fantastic! Mille mille graze!

Eloisa introduces her colleague

Cristiano Leorin, Vice President of Novilunio.

Thank you very much. Firstly, I want to say a real thank you to Chris and Helena who we saw before, because I'm a speech and language therapist and I saw that they were participating and talking. I love it; and because it's nice to see if there are any communication problems that people are trying, what they are doing and saying what they need to say, and not only what their caregivers say, for example. That's something that I really like – thank you very much for participating today.

Empowerment

One of our keywords at Novilunio is empowerment. So the idea is that the people that are participating, this group, as Tiziano was saying, is nice because when they arrive, it's like a group of friends that are meeting, gathering, drinking coffee, laughing, meeting, usually to start at 10:30 and finish at twelve. In actual fact, we tend to start at ten and finish at 1pm because nobody wants to leave. And we are there talking, chatting, discussing and trying to find out solutions.

Improving quality of life, members free to speak their mind, inonn-judgmental and nclusive.

Our prime object is to improve quality of life for all of us. That's very nice because we are there and we are discussing and everybody can say what they need to say. You can say whatever you want. And that's very nice, because we are there altogether and we are not separate. Sorry for the caregivers, but we are separate from the caregivers. So in our group there are only people with diagnosed dementia, every kind of dementia, because it's very heterogeneous in our group. We are there discussing, laughing, crying sometime and sharing. So inclusivity is another word that I want to draw attention to.

But that's enough from me, because I want to introduce our special guest, that is Francesco.

CL introduces Francesco Parisotto 'Frank'

I will say a few words about him, because also Francesco is very young. He lives with Cadasil, a rare form of genetic vascular dementia, and is a really passionate advocate about Cadasil. Frank was a mechanic and sales consultant and worked for the Civil Protection Association for 25 years. So for a long time he was devoted to other people. As his mother also suffered with Cadasil, he had long known what it means. Frank lives an hour outside Padua. So every time that we meet, he and Fanny are traveling to Padua. They usually arrive with lots of coffee – our special coffee machine.

Frank's poetry

Frank is here today because he really likes, loves to write poems. We have already heard about the importance of poetry. Frank has written sixty poems. So tonight, specially for you, we will have a reading from Frank about a choice of one, maybe, - Veronica translated these poems into English. I will ask Francesco to read the first one in Italian, so you can also listen to his voice. Then I will just have one question, (because time is short) and just to ask one thing to Frank. But before that, please, Frank, can you read Ascoltami

Frank recites in Italian.

Ascoltami	**Listen to Me**
Ascoltami	Listen to me
perché non senti	Because you don't hear
lo grido il mio dolore	I cry out my pain
Nessuno ascolta	Nobody is listening
Ascoltami	Listen to me
Sento esplodere la mia vita	I feel my life is exploding
Mille pezzi vagheranno	A thousand pieces will drift away
Nessuno si poserà	Not one will settle
Nessuno si ricorderà	No one will remember
Ascoltami	Listen to me

CL Thank you, Francesco.

On the importance of listening to the person

As you can see from the translation, I think this is something that everybody, who is needing some help, is asking to all the world just to listen, but not just hearing. It's really listening to something. So I'm crying. I'm saying that there is something that is not going well. So please listen to me, please. Nobody is listening. And that's something we discuss in our groups: I have not somebody to talk really freely about what I feel inside. That's why the group, because in the group, nobody's paying any attention to the word you mean to say, if it's the right one. That's not important. The listening is very important.

So my question to you, Frank, is :

Cosa significa per TE scrivere POESIE. Cosa TI regala questa passione? What does it really mean to you to write poems, this passion you have.

Frank *Per me scrivere POESIE, e pesternare I miei sentimenti, cercare di guarire l'anima, communicare con le persone cercando un po' di empatia*

For me, writing POEMS and expressing my feelings, trying to heal my soul, communicating with people looking for a bit of empathy.

Voglio scrivere e parlare per sentirmi vivo I want to write and speak to be alive

Voglio portare la mia esperienza e come affront le dofficolta. Non voglio arrendermi.
I want to share my experience and how I deal with difficulties. I don't want to give up

Voglio essere utile a chinque si trovi ad affrontare come me una DIAGNOSIi di DECADIMENTO COGNITIVO perche ‘DIAGNOSI non vuol dire FINE, ma CAMBIAMENTO’ e sparanzo nel futuro.

I want to be useful to anyone who finds themselves facing a DIAGNOSIS of COGNTIVE DECAY like me because ‘DIAGNOSIS does not mean END, but CHANGE’ and I am looking forward to the future.

Giornata	**The Day**
E' stata una bella giornata	It was a beautiful day
un po' dura, ma bella.	A little tough, but beautiful,
Il fato é stato clemente	Fate was kind
Il destino un po' irriverente	Its destiny somewhat irreverent
Il mio passo forte e sicuro	my step strong and sure
Guardando con occhi da bambino	Seeing with child’s eyes
il mio passato ormai lontano	my almost distant past
con il futuro in mano.	the future in my hand.
Futuro incerto	Uncertain future
Futuro da costruire	A future to build
Futuro da sostituire, con speranza,	A future to replace, with hope,
ed un po' di arroganza.	and a little arrogance.

Frank relates Cognitive Impairment to the art of piano playing

Come i tasti di un pianoforte BASTA TOCCARE QUELLI GIUSTI
Like the keys on the piano – you just touch the right ones

When one plays a piano, one can miss keys, or go out of tune because the keys are not in tune. Well, this also happens to us people with cognitive impairment, we just need to touch the right words, perhaps distant memories, those sometimes blurred moments, and everything returns to COLORS.

Colori	**Colours**
Ricordati di stendere i colori della vita	Remember to value the colours of life
non lasciare che il GRIGIO sovrasti	don’t let GREY dominate
Usa il ROSSO per amare	Use RED to love
Il ROSA per sognare	PINK to dream
il BLU per volare	BLUE to fly
il VERDE per giocare	GREEN to play
il BIANCO per viaggiare	WHITE to travel
Dolci, leggere pennellate sui tuoi sogni.	Sweet, light brushstrokes as you dream.

How empathy and emotion can reawaken memories

A volte la memoria fa cilecca, ma le emozioni rimangono, e facendo leva su quelle possiamo risvegliare ricordi che sembravano persi o dimenticati, ma erano solo addormentati in attesa dei “tasti giusti”.

Sometimes memory fails, but emotions remain, and by leveraging our emotions we can reawaken memories that seemed lost or forgotten, but were only asleep waiting for the "right buttons".

CHAT
Jane Ward Would love to hear more from Frank - brilliant
Veronica Frank, your poetry, the pieces drifting away - reminiscent of Seb's film Mille pizza vgheranno

CL, co chair Thank you very much, Frank. in a nutshell, what Frank was saying is that he's writing poems just to express the feelings. And this for him is like, heal the soul, communicate the people by seeking a bit of empathy. So he was talking about empathy a lot of time. His message for us all of us is: Never give up. Never give up because we have to fight.

ES, co-chair Actually, it's the motto of the two of them. The beautiful lady that you see right next to him, Fanny, is his wife. And her motto is always never, never give up.

Diagnosis does not mean the end. It is a beginning of … a new kind of life

CL, co-chair That's it. Another motto is: Diagnosis does not mean the end. It is a beginning of something else. It's a new kind of life. But it's something that you can also hope for a change. That's another thing that Frank was saying. I also have to say thank you to Frankie, because in our group, lots of the time, the other people are saying, *OK, you can do that, no worries*. *You can do that, no worries. We are together* We can do something together. That's something we really like in the group. But I think that sometimes, even if you do not have the right words, even if you are not saying exactly what you are thinking, but speaking from your soul, you really know what you want and you can see from the people how they look at you, how they listen to you, how they are taking care of you.

CL, co-chair We were discussing this also in the group with some doctors, psychologists who are sometimes not really s listening to you, but just hear things. So that's the perspective from our group. Thank you very much, Frankie, and thank you very much, Fanny and thank you very much, Tiziano, for your help and testimony to our president. Thank you to everybody. Thank you, Veronica, for inviting us. Tor sure., thank you, Veronica. I met her in Naples and was so nice.

Veronica, A4D, host Thank you so much. It's ever more wonderful to see and hear you and to see all your members. Actually, I was going to express it in Italian! *Grazie mille a Cristian, Eloisa, Tiziano e Frank, le vuoi poesie sono davvero audace e fonte di ispirazione per tutti noi.* – Thank you so much Cristian, Eloisa, Tiziano and Frank – your poetry is truly bold and inspirational.

I love to hear you say it empowers you to new adventures together. And I love all your smiles and your talking from your soul, as indeed everything that Seb and Charlie, Chris and Andrea, Helena and David, Monica, Tony and Bec - all our speakers been absolutely amazing, have given really valuable insights into how,, despite each diagnostic challenge, cultural and creative activity can make such a difference to life.

It was particularly moving when we were preparing for this Conversation today, to hear Helena spring up – David too - when she was telling us about RDS's music partnership, Out of the Ordinary, with the Wigmore, and how fantastic it was to be offered that when they were facing the dark trauma of diagnosis and to be immediately lifted by RDS offering the programme. Seb and his team made an enormous difference to her, as he and Charlie and Eloisa and Cristian do to all your members.

I should like to draw your attention too to this American study, How a rare dementia transforms patients into artists. This was research led by Adit Friedberg of the University of California in San Francisco., who was not able to join us, but their study explains the brain. changes that promote visual creativity.

Thank you all so much for joining us and mega thanks to our chairs, Seb and Charlie and Eloisa and Cristian, who is amazing to see. I do hope we won't lose touch. Frank and Tiziano, Helena and David, Chris and Andrea, you are inspirational!

Finally, very warm thanks for technological guidance and support to **Nigel Franklin**, A4D Associate and **Amisha Palmer**, Greengross A4D Global Arts for Brain Health Coordinator

Veronica adds: Our next Greengross A4D Global Arts for Brain Health Changemakers Conversation is going to involve International SP Student Champions, on Social Prescribing Day, Thursday 14 March. And then for World Refugee Day, we shall be discussion practice for refugees, including A.R.T. Art for Refugees in Transit of New York

CHAT

Tibbs Foundation, Bedford I will be taking all of this back to our group and it just resonates so much with us because we art based groups and music groups, **Veronica** It's so special intergenerational work that you do in Bedford.

Fernando José Carvalho Congratulation for this conference, and for all experiences shared, it was amazing. Additionally I want to make a question/tip, what do you think about Heat Shock Proteins Therapy in dementia, specially with targeting at HSP60, HSP70 and HSP90, thank you.

Fernando José Carvalho If you want to create a partnership with our **organization, High Performance Brain, let us know please, we are available to do it, thanks**

Bisakha Sarjer The picture istruely shows what love of one's life nean

sumita chauhan Thanks everyone. It was very inspirational to hear about so many approaches and personal experiences. Made me aware of different perspectives, I would like to hear more about social prescribing if you arrange another meeting.

kate white Thank you ++++

Stephen Deazley Thanks everyone for sharing your practice, experience, stories and art today

debi miller Really interesting afternoon.

Anne Stegmann Thank you! Excellent !

Sarah Russell It has been so special to listen today. Very inspiring and uplifting. Thank you so much

sinead Devine Thank you .Great to see such wonderful work but unfortunately I must leave now.

Sarah Russell I would love to share your Poem with our groups Frank, if that is possible

Jemma S Thank you so much to you all for great Conversation, poems and arts, it has been really fascinating. However I do need to leav now.

Tim OBrien 👏👏 a Padua!

Claire Street Thank you so much. Fascinating work

Jemma S Thank you and Grazie!

Jane Ward Thanks for joining from Italy

Karen Murrell Thank you so much for this - look forward to having access to the transcript and edited video - and to the next one!!

Ian Witterick Thank you Veronica for arranging the event.

Claire Street Many thanks.

Monica Boulton Thank you everyone - feeling very inspired and encouraged!

Jacquie Nunn Thank you everyone.. A very inspiring afternoon.

Tim OBrien Thank you also to Veronica for making this inspiring event happen. **Veeronica –** much appreciated, Tim

Karen Murrell Thank you - hope to come to more

Jane Ward Thanks for a great session

anna twells Just a shout out for Creative Minds, lots of amazing artists across the UK doing work in care homes and for other groups 🙂 and one to one sessions

kate white Its' wonderful to hear about the provision of support over time by through the RDS network. Continuity is of the essence being known and understood over time is crucial for us all but particularly when we are feeling vulnerable and needing support. The NICE guidelines do say there should be one point of contact over the lifetime of people living with dementia. I think there is a need for relationship over time attachment theory has a lot to say on our need for others. The finding of opportunities is so fragmented. Fragmentation is very costly as not enough people attend than the funding is withdrawn. Things need time to grow and develop.

kate white assessment as a collaborative and interpersonal process. I recall a moment when my partner who had been diagnosed with Alzheimers so not a rare dementia - he was being taken through the usual memory assessment and he was asked about what season were we in? As language was more challenging at this point he started whistling the tune "Autumn Leaves" which being a jazz pianist came totally naturally to him. The assessors didn't get it and looked bewildered!! It was the end of October by the way.

kate white Love the international conversation …We at the Dementia Community invite you all to join us!!
https://journalofdementiacare.co.uk/dementia-community-membership
Dementia Community's vision is of a world where all people feel connected, informed, empowered and purposeful; actively engaged in co-producing changes that improve everyone's experience of dementia, both in care and in wider society.Dementia Community is the new name for the organisation that:Publishes the Journal of Dementia Care Produces the UK Dementia Congress Provides the National Dementia Care Awards Connects and empowers the Dementia Community

CONVERSATION **4**

International Social Prescribing Champions: Thursday 14 March 2024

Greengross 'Social Prescribing Student Champions' Conversation (Thursday 14 March 2024)

On Social Prescribing Day 2024, the National Academy for Social Prescribing (NASP) launches The Social Prescribing Student Champion Scheme report *7 Years On!* with insights from SP Student Leads from the UK, Australia, Canada and the United States.

HOST

110 **Veronica Franklin Gould**, President, Arts 4 Dementia

111 **Dr Bogdan Chiva Giurca**, Clinical Lead and Global Director of NASP launches The Social Prescribing Student Champion Scheme report *7 Years On!*

118 **CHAIR: Hamaad Khan**, NASP Global Development Officer.

PANEL 1: The Role of the SP Student Champion Scheme.

119 **Charlotte Osborn-Forde,** Chief Executive Officer, NASP.

120 **Nicola Gitsham,** Head of Social Prescribing at NHS England.

PANEL 2: Conversation with UK SP Student Champions.

123 **Kirstie Goodchild**, SP Student Champion Evidence Lead.

125 **Naabil Khan,** SP Student Champion Global Lead.

127 **Alexandra Tan**, Student Champion Social Media Lead.

PANEL 3: Conversation with International SP Student leaders.

130 **Abbey Deguara**, Co-lead, AMSA Social Prescribing Student Collective, Australia.

132 **Maddie Maier,** Chair, US Social Prescribing Student Collective, and founder of the Harvard Undergraduate Initiative for Social Prescribing.

134 **Le-Tien Duong Bhaskar**, Co-Lead, Canadian Social Prescribing Student Collective

137 **PANEL DISCUSSION** – chaired by **Hamaad Khan.**

THE CONVERSATION

Veronica Franklin Gould, President, Arts 4 Dementia

Hullo, Happy Social Prescribing Day! and welcome to you all, to our speakers – each a leader in their field - and to delegates from Australia, Austria, Canada, Egypt, Ethiopia, Germany, Ireland, Malta, Nepal, Nigeria, Switzerland and from around the UK and the United States of America.

Today we are honoured and indeed proud to celebrate the Social Prescribing Champion Scheme founded in 2015 by the then Exeter University medical student, our chair for this event, Dr Bogdan Chiva Giurca. now Clinical Lead and Global Director of the National Academy for Social Prescribing (NASP), with an International Programme convening leaders from over 32 countries worldwide.

Baroness Greengross in whose memory these Arts for Brain Health Changemaker Conversations are held, would be thrilled by the growth and achievements of the Social Prescribing Champion scheme, which encourages and enables healthcare students to spread the practice of social prescribing and the key biopsychosocial model of health in education.

With regard to Arts for Brain Health, this life-transforming biopsychosocial practice – GP referring patient to their primary care link worker, to plan stimulating arts programme as treatment – can from the very onset of a potential dementia empower people to preserve their brain health. For example, an Arts 4 Dementia drama participant diagnosed with vascular dementia following a stroke, found that after a year of weekly art and drama, her reading ability and short-term memory had so improved that her diagnosis was revised to stroke damage. Of course, few people have their diagnosis reversed, but it does show the impact of active arts on prescription in enabling people to live better for longer with dementia.

So we are hugely grateful to Bogdan and his co-chair Hamaad Khan for gathering together a cracking team of speakers. To open, Bogdan will explain the Social Prescribing Champion Scheme and launch the *Seven Years On* report.

Hamaad will chair three panels of experts: The first with **Charlotte Osborn-Forde**, the chief executive of NASP and **Nicola Gitsham**, who is the Head of Social Prescribing at NHS England. The second panel, brings insights from UK Social Prescribing Student Champions – **Kirstie Goodchild,** the Evidence Lead, **Naabil Khan** Global Lead and **Alexandra Tan**, the Social Media Lead – and the third panel introduces a variety of international approaches from **Abbey Deguara** of Australia. **Maddie Maier** from Harvard and the United States and **Le-Tien Duong Bhaskar**, from Canada. As access to social prescribing differs around world, these insights will be fascinating,

We then invite you to pose questions for our speakers for the Q&A and finally, in summing up, Hamaad will discuss the Future of Championing Social Prescribing. Now it gives me great pleasure to introduce our co-chairs Dr Bogdan Chiva Giurca and Hamaad Khan:

Dr Bogdan Chiva Giurca is a medical doctor. Now Clinical Lead and Global Director of the National Academy for Social Prescribing(NASP). Bogdan has played a key role in the development of Social Prescribing since 2015, establishing and chairing the NHS England Social Prescribing Champion Scheme. Bogdan lectures at Imperial College London, leading the Social Prescribing module. He is an Honorary Lecturer at University College London and a Collaborator for the Harvard Global Health Institute. In 2022, the *Health Service Journal* named Bogdan among the 'Top 100 Most Influential People in Health' in the UK.

Bogdan Thank you very much, Veronica, for a very humbling, introduction and we are very grateful to your leadership and mentorship. Across the years, Veronica, it's thanks to you that we've all got together not only today but over the years and we are very thankful for that.

National
Academy
for Social
Prescribing

Social Prescribing Champion Scheme

Dr Bogdan Chiva Giurca
Clinical and Global Lead for Social Prescribing
National Academy for Social Prescribing
Harvard Global Health Institute Collaborator
Honorary Lecturer, University College London
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Now I do wish we were in person because as many of you will know and I've seen some very familiar names on the chat and we usually get together in person on social prescribing day and there's many hugs being shared than many many kisses and we congratulate each other for the work that we've all done and special thanks to those present today, especially I've noticed Professor Helen Stokes-Lampard who has played a crucial role in us getting this off the ground over the years, as well as Debs who is one of the most magnificent people that you should all speak to and Google The Debs Effect, as well as many others who you'll be hearing from shortly as part of the main stage, as well.

CHAT

Helen Stokes-Lampard Thank you for the namecheck Bogdan, sadly I am only here for first 30mins but wishing you all a hugely HAPPY SOCIAL PRESCRIBING DAY. Thanks to Veronica and the team for hosting this great event. Warmest wishes all. H **Hamaad**, @HamaadAKhan : ❤️

Jez Hughes Great to see so many here and pleased to be an Ambassador for Age Irrelevance. Jez (formerly Jeremy) Hughes.

Veronica FG, host: Jeremy/Jez - warm welcome! Age Irrelevance is the foundation set up IN memory and to further the legacy of Baroness Greengross, who devoted her working life to improving the lives of older people and those with dementia, then supported youth work, Our Greengross webinars aim to carry forward this work.

Veronica It is a great honour to welcome you Helen, and Jeremy who have done so much for this exciting movement to promote brain health and wellbeing **Helen Stokes-Lampard** ❤️

Jez Hughes :Nobody should underestimate the enormous commitment of Bogdan in getting to where we are today.

Debs@TheDebsEffect :Thank you for your commitment and passion too Bogdan, I don't think the students would be anywhere near where they are without your passion and input

Dr Nermeen Hamdy, Associate Professor, Cairo, University, Egypt :Thanks Bogdan

It's a great joy to be here with you. I was once a medical student. In 2015 I started getting involved in social prescribing (SP) thanks to many mentors who are pushing me into this realm of preventative medicine and prevention being better than pills themselves and better than the cure.

The Social Prescribing Student Champion Scheme 7 years On

National Academy for Social Prescribing

The Social Prescribing Student Champion Scheme:
7 Years On (2016 - 2023)

Primary Objective

To modify university curricula, ensuring that social prescribing, personalised care, and social determinants of health are integral components of the foundational education for medical students, as well as for nursing, midwifery, and various allied healthcare professional graduates.

The Mechanism

Establishing a student movement focused on health creation and disease prevention, advocating for social prescribing and personalised care through peer teaching at UK-based universities.

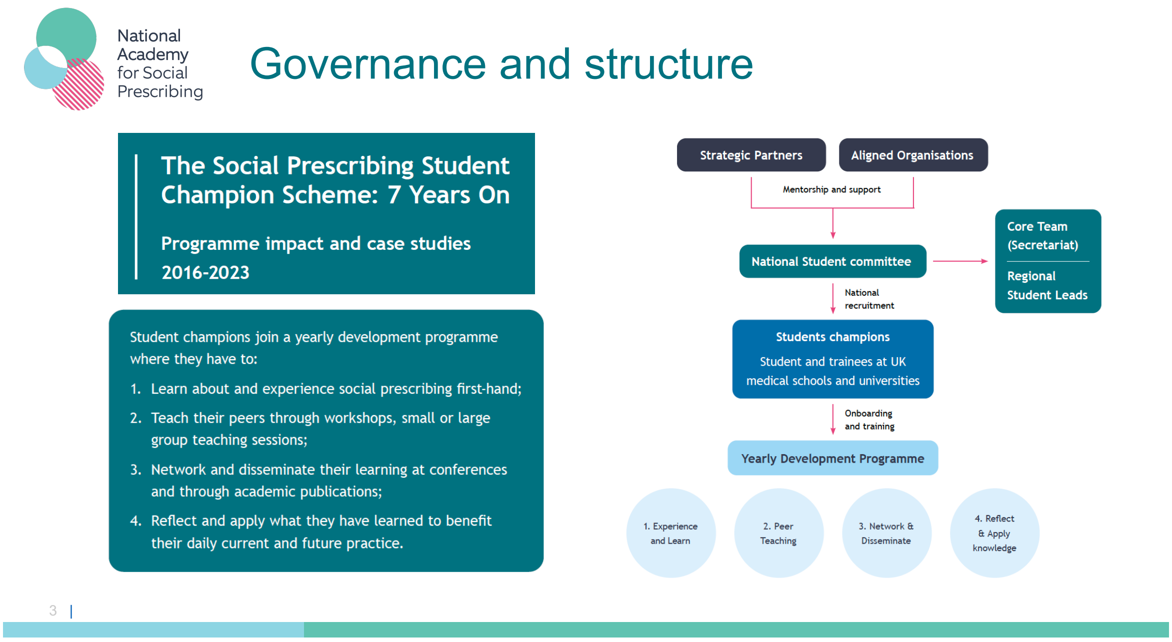
We have recently put together the *7 Years On* report. I will just give an outline of the main findings. It's a report following seven years on from the development of the programme, which was founded in 2015. The activity started in 2016 – almost eight years now in the making.

The Social Prescribing Champion Scheme

The main objective of the SP Champion programme was to modify the university curricula to ensure that concepts such as SP and personalized care are at the forefront of our future health care professionals' set of toolkits. We wanted to make sure that it takes as much priority as suturing does and all the other concepts that medical students get taught. Many of us were quite frustrated because we were taught algorithmic thinking that if X then Y, if high blood pressure then prescribed this pill if someone is feeling lonely, however, we were missing some algorithm sets and we weren't taught in full what we should do in such circumstances.

Starting student movement to focus on health creation and disease prevention – SP

So we started recruiting medical students initially, but then involved across the wider spectrum of Allied Health Professionals (AHP) as you'll see in a second. The mechanism for achieving that change in the curriculum was developing a student movement focused on health creation and disease prevention and advocating the SP and personalized care to be added at the core of the teaching that is being delivered in the medical schools. This is how it was done, the government governance model that we had that time.



National Academy for Social Prescribing

Governance and structure

The Social Prescribing Student Champion Scheme: 7 Years On

Programme impact and case studies 2016-2023

Student champions join a yearly development programme where they have to:

1. Learn about and experience social prescribing first-hand;
2. Teach their peers through workshops, small or large group teaching sessions;
3. Network and disseminate their learning at conferences and through academic publications;
4. Reflect and apply what they have learned to benefit their daily current and future practice.

Strategic Partners

Aligned Organisations

Mentorship and support

National Student committee

Core Team (Secretariat)

Regional Student Leads

National recruitment

Students champions

Student and trainees at UK medical schools and universities

Onboarding and training

Yearly Development Programme

1. Experience and Learn

2. Peer Teaching

3. Network & Disseminate

4. Reflect & Apply knowledge

We had a series of strategic partners which I'll outline in a second and a series of aligned organizations and mentorship and support from amazing people, many of whom are today in the room with us.

The growth of student champions

We had a national student committee formed between a secretariat and a group of regional leads. We selected one student champion from each university across the UK, mainly medical schools, then expanding to nursing, midwifery, occupational therapy, physiotherapy, pharmacy, and so forth.

We simply ask them to do four main things.

1) They have to experience and learn about SP themselves.
2) Once they learned that themselves, they had to lift someone else up. They had to share the knowledge with some of their peers. That could have been done through small group teaching or large group teaching or as part of the university lectures that were happening at the time. The university lecturers welcomed this support from the students because these were subjects that students sometimes didn't really pay attention to. They were quite often regarded as wishy washy, sadly, and seen as not as important as the muscles and the bones in the anatomy teaching that we got, although we know that and that such subjects are of equal importance based on the recent demographic and rising social inequality and social determinants of health that we've seen.
3) They had to network and disseminate the information that they developed over the over their medical school and their region
4) They had to reflect and apply that knowledge in their own career, be it in exams, be it in papers or publications or disseminating this further at conferences.

National Academy for Social Prescribing

Programme Highlights: 7 Years On

Programme Highlights: 7 Years On

782 student champions recruited to date

20,000+ healthcare trainees and students engaged

1,500+ teaching sessions delivered across UK universities

50+ Conferences and published multiple peer-reviewed publications presented by Champions

3x National Conferences with over 500 attendees

83 Universities involved

Launched world's first **#SocialPrescribingDay** awareness campaign (2018)

Social prescribing is now being taught at **all UK-based medical schools**

Launching the #SocialPrescribingDay Campaign (2018)

Most notably, the student group founded the international #SocialPrescribingDay campaign in 2018. This represented a humble offering from tomorrow's doctors and health professionals on the NHS 70th birthday. The campaign was officially launched during a keynote presentation at the King's Fund annual conference.

What's fascinating to see is this slide on its own depicts the incredible effort that's students and young trainees or not just students but young doctors young trainees have achieved over the past few years. And as Veronica said, I did create this student movement initially, but as much as I'd like to take credit for it, I have done very little. It's really all about us all together as a group and each and every single one of the 20,000 students involved.

To date we've recruited more than 782 student champions across the universities and engaged with more than 20,000 students and young trainees. We've delivered over 1,500 and teaching sessions at UK based universities as well as attending over 50 conferences and publishing several peer reviewed academic papers and as well as making sure that teaching is being delivered at 83 universities across the UK.

So not only over the course of seven years we made sure that teaching is being delivered at those universities, including all 44 medical schools, but also in addition at 40 other and AHP universities including courses for pharmacies, nurses, midwives and others as well.

SP Day campaign launched on NHS 70th birthday, at King's Fund Conference

A little secret that not many of you will know is that in 2018 – on the NHS seventieth birthday – we launched the SP Day campaign. So today Happy Social Prescribing Day is thanks to the students and the trainees who put together and this offering it was a humble offering, a present from the future generation of tomorrow to the NHS on its seventieth birthday, launched at the Kings Fund in a conference that many of you will remember where a very young and inexperienced medical student – myself – gave a speech on behalf of the future generation of health professionals. What's interesting to see is how the SP movement, the campaign lives even today, trending forth all over the UK. Thank you all for tweeting #SocialPrescribingDay. It was fourth, competing with Cold Play As much as I love Cold Play, I think SP deserves to be higher up than than them at the moment – I hope you all agree!

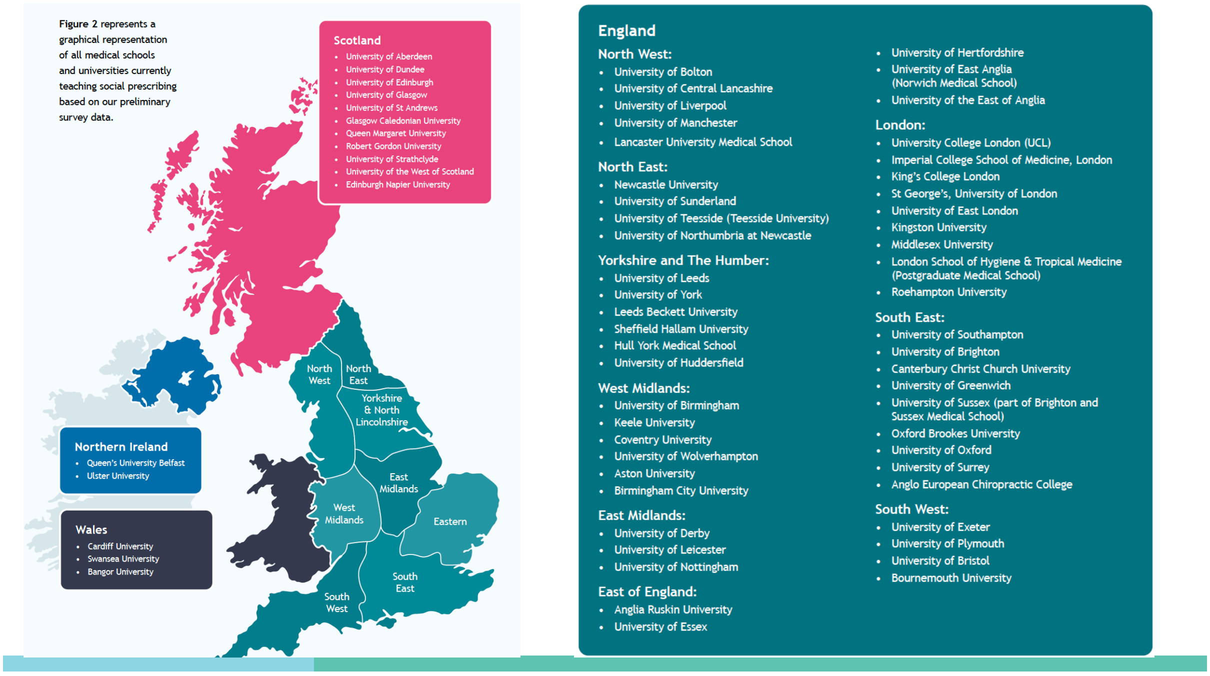


Figure 2 represents a graphical representation of all medical schools and universities currently teaching social prescribing based on our preliminary survey data.

Scotland
- University of Aberdeen
- University of Dundee
- University of Edinburgh
- University of Glasgow
- University of St Andrews
- Glasgow Caledonian University
- Queen Margaret University
- Robert Gordon University
- University of Strathclyde
- University of the West of Scotland
- Edinburgh Napier University

Northern Ireland
- Queen's University Belfast
- Ulster University

Wales
- Cardiff University
- Swansea University
- Bangor University

England

North West:
- University of Bolton
- University of Central Lancashire
- University of Liverpool
- University of Manchester
- Lancaster University Medical School

North East:
- Newcastle University
- University of Sunderland
- University of Teesside (Teesside University)
- University of Northumbria at Newcastle

Yorkshire and The Humber:
- University of Leeds
- University of York
- Leeds Beckett University
- Sheffield Hallam University
- Hull York Medical School
- University of Huddersfield

West Midlands:
- University of Birmingham
- Keele University
- Coventry University
- University of Wolverhampton
- Aston University
- Birmingham City University

East Midlands:
- University of Derby
- University of Leicester
- University of Nottingham

East of England:
- Anglia Ruskin University
- University of Essex
- University of Hertfordshire
- University of East Anglia (Norwich Medical School)
- University of the East of Anglia

London:
- University College London (UCL)
- Imperial College School of Medicine, London
- King's College London
- St George's, University of London
- University of East London
- Kingston University
- Middlesex University
- London School of Hygiene & Tropical Medicine (Postgraduate Medical School)
- Roehampton University

South East:
- University of Southampton
- University of Brighton
- Canterbury Christ Church University
- University of Greenwich
- University of Sussex (part of Brighton and Sussex Medical School)
- Oxford Brookes University
- University of Oxford
- University of Surrey
- Anglo European Chiropractic College

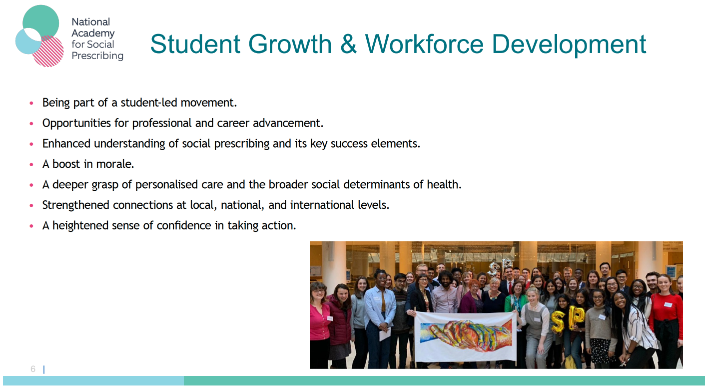
South West:
- University of Exeter
- University of Plymouth
- University of Bristol
- Bournemouth University

This list of the universities where SP has been officially embedded into the curriculum is part of our recent study and survey and what's fascinating is that over the years, students try to get the General Medical Council (GMC) to include this in their official curricula and our request was declined from the GMC. However, the students did not hold back.

The Revolution of the Peasants

They continued peer teaching one another and the deans of the medical schools and started noticing that the students were pure teaching each other through societies and have decided to ensure that this is formalized and added officially as part of the curricula. It's absolutely astonishing. There's been a quote running around that this is called the Revolution of the Peasants and the students are the lowest of the ranks who made this possible and I find this highly inspirational and certainly would have not been possible without the support of our great mentors and without the support of students in every single one of the universities.

I'm a big believer that this movement could be replicated for many other subjects. At the time SP was much needed. It is still needed and one of the subjects lacking in the curriculum of not just medical schools but other AHPs. In terms of what the students got out of it, this is very interesting. When we did this survey across all our champions, what was very interesting was seeing what they got out of it. Largely after thematic analysis, they all said that they love being part of a student-led movement. They created their fortune. They created, they left a bit of an imprint and the thumbprint into the healthcare system and they successfully shaped the future of tomorrow. They also had opportunities for professional



National Academy for Social Prescribing

Student Growth & Workforce Development

- Being part of a student-led movement.
- Opportunities for professional and career advancement.
- Enhanced understanding of social prescribing and its key success elements.
- A boost in morale.
- A deeper grasp of personalised care and the broader social determinants of health.
- Strengthened connections at local, national, and international levels.
- A heightened sense of confidence in taking action.

6 |

and career advancement. They were able to get certificates, publications out of it. They had an enhanced understanding of how clinics work and how they'd be able to use those things and they had a huge boost in their morale.

I hope I speak on behalf of Hamaad and the other young trainees present today because for me personally it's one of the reasons why I've stayed in medicine. SP has been the light at the end of the tunnel for me to realize that we are able to treat, people, patients as human beings, not as recipients of our pills and procedures. That has been a massive boost in morale for myself. Each of us has had a heightened sense of confidence in taking actions and being able and to ask for such tools to be used more often in our clinics.

I will pause here because I'd love you to read these quotes, particularly the one on the right, from Leah, who I think is now a doctor. These are yesterday's students from 2015, today's health care professionals. Many have been with the scheme since their first year of medical school. The scheme has got them through the medical school process and they are now doctors or occupational therapists or physiotherapists. Their quotes are astonishing.

National Academy for Social Prescribing

Yesterday's students… today's healthcare professionals

"Embarking on my journey with the Social Prescribing Student Scheme right from the start in 2016 was a decision that profoundly shaped my medical career. Over five transformative years, the programme ingrained in me a deep appreciation for holistic healthcare approaches, emphasising the human side of medicine beyond diagnosis and treatment. Now, as a junior doctor, this approach is integral to my clinical work. It's not just about treating conditions but understanding patients' unique stories and environments, which has become a cornerstone of my daily clinical practice."

Dr Daisy Kirtley
(Junior Doctor)

"I became the AHP coordinator for the scheme in November 2021 when I started my MSc in Occupational Therapy at UEA and have been a member since! I have loved raising awareness of the usefulness of social prescribing for AHPs by delivering lectures, speaking at the national social prescribing conference, and publishing research on best practice for teaching AHP students about social prescribing."

Kirstie Goodchild
(Occupational Therapy Student)

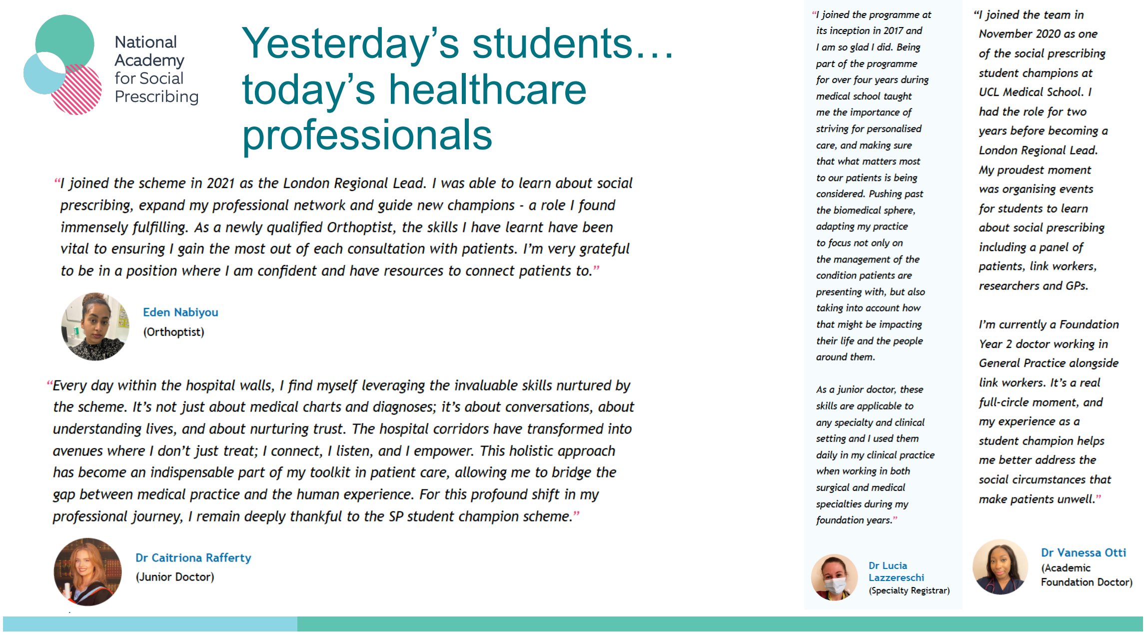
"The scheme is one of the things I am most proud of from my time as a student. In leading the Allied Healthcare Professional branch of the scheme, I really got a sense of multidisciplinary working, learning about the other professions I now work along side clinically. And of course, it helps cement in my mind the power of social prescribing, and thinking outside our NHS box when working with patients."

Anya de Iongh
(Occupational Therapist)

"I joined the Social Prescribing Scheme in my first year of medical school, working through the scheme from a champion all the way to General Secretary. Four years on, I'm now in my second year as a doctor and use the skills and knowledge I gained throughout the social prescribing scheme every single day. In my current job in primary care, my practice has an amazing social prescriber and I utilise their expertise for patients that the traditional medical model falls short for. My understanding and appreciation of their role, all developed through my work within the Scheme, means I can utilise their skills to optimise patient outcomes which I have had the privilege of now watching firsthand."

Dr Leah Crabtree
(Academic Foundation Doctor)

I urge you all to screenshot and put them on Twitter #SocialPrescribingDay for others to see how it truly portrays why they've done this and how it has allowed them to use those skills in their day-to-day job. Here are more, from doctors, an orthopaedist saying that she was able to learn about SP and use it in her clinic.



National Academy for Social Prescribing

Yesterday's students… today's healthcare professionals

"I joined the scheme in 2021 as the London Regional Lead. I was able to learn about social prescribing, expand my professional network and guide new champions - a role I found immensely fulfilling. As a newly qualified Orthoptist, the skills I have learnt have been vital to ensuring I gain the most out of each consultation with patients. I'm very grateful to be in a position where I am confident and have resources to connect patients to."

Eden Nabiyou
(Orthoptist)

"Every day within the hospital walls, I find myself leveraging the invaluable skills nurtured by the scheme. It's not just about medical charts and diagnoses; it's about conversations, about understanding lives, and about nurturing trust. The hospital corridors have transformed into avenues where I don't just treat; I connect, I listen, and I empower. This holistic approach has become an indispensable part of my toolkit in patient care, allowing me to bridge the gap between medical practice and the human experience. For this profound shift in my professional journey, I remain deeply thankful to the SP student champion scheme."

Dr Caitriona Rafferty
(Junior Doctor)

"I joined the programme at its inception in 2017 and I am so glad I did. Being part of the programme for over four years during medical school taught me the importance of striving for personalised care, and making sure that what matters most to our patients is being considered. Pushing past the biomedical sphere, adapting my practice to focus not only on the management of the condition patients are presenting with, but also taking into account how that might be impacting their life and the people around them.

As a junior doctor, these skills are applicable to any specialty and clinical setting and I used them daily in my clinical practice when working in both surgical and medical specialties during my foundation years."

Dr Lucia Lazzereschi
(Specialty Registrar)

"I joined the team in November 2020 as one of the social prescribing student champions at UCL Medical School. I had the role for two years before becoming a London Regional Lead. My proudest moment was organising events for students to learn about social prescribing including a panel of patients, link workers, researchers and GPs.

I'm currently a Foundation Year 2 doctor working in General Practice alongside link workers. It's a real full-circle moment, and my experience as a student champion helps me better address the social circumstances that make patients unwell."

Dr Vanessa Otti
(Academic Foundation Doctor)

It's inspiring to see how the students we taught from Year One are now fully fledged doctors, orthoptists, physiotherapists, pharmacists using those skills in their day-to-day practice.

It really is changing the future of health care one student at the time, one health professional at a time. We'd like to think that our efforts haven't been in vain. In fact, we know they haven't because we know that SP has now been adopted at every single university in the UK, especially at the medical schools.

A huge thank you to the organizations involved, particularly NHS England who's been with us from the beginning, even before NASP was founded initially by the then Secretary of State for Health and two individuals who've been at the core of this, and Nicola Gitsham and Beth Taylor, who many of you will remember who've been mothers of SP for us and mentors for us all. And of course, when NASP was funded, they offered us incredible support: Studentships and bursaries for the students.

I'm delighted to announce that the Student Champion Scheme continues under the mentorship and support of the National Academy of Social Prescribing, our CEO Charlotte Osborn-Forde and is a big fan of the student and young trainee movement and has supported the programme ever since the development of the National Academy and we are very grateful. And of course, we're grateful to the other organizations. But grateful to you, Veronica, for your mentorship and grateful to all the Royal Colleges involved in the delivery of this programme.

It does seem that the future is very bright and I hope you think so after you hear from Hammad and some of the other students on the call, particularly as we've now expanded into Australia, Canada, US, Portugal, Singapore and all over the place. Students are demanding better care for their future patients. They may not be doctors today, but they will be doctors tomorrow and they are demanding better care because we know what's available at the moment isn't enough and we want to make sure we see people as human beings not as simple recipients of our treatment.

With that in mind, I thank you all for listening and I hope you enjoyed this short presentation and I pass over to Hammad. He's been a pioneer of the programme himself and a great role model for many and someone who joined from a neuroscience background but completely changed his perspective in terms of what medicine involves. Hamaad will tell you more and introduce the rest of the speakers. Thank you.

Hamaad Khan, NASP Global Development Officer,

A busy medical student, Hamaad is Global Development Officer for NASP and co-leader of the Global Social Prescribing Student Council. He is dedicated to advancing global health systems with a focus on health promotion and disease prevention. He has a Neuroscience degree from King's College London and MSc in Global Health and Development from University College London. He collaborated with the World Health Organisation to author the first global SP report., *Social Prescribing Around the World*. As a neuroscience student referred by Bogdan, his involvement in Arts 4 Dementia's 2020 drama programme, interacting with participants and supporting the evaluation, yielded mutual learning for which we were most grateful. Hamaad was the youngest-ever recipient of the Hillary International Award for Health & Care Leadership.

Hamaad chairs the three Conversation Panels:

PANEL 1: The Role of the Social Prescribing Student Champion Scheme, its importance in shaping future doctors and healthcare professionals.

The purpose and value of SP in modern healthcare systems

Bogdan has given an incredibly inspiring talk and I hope everyone enjoyed that. As we continue on with this webinar, I think one of the most central questions that we're going to be asking whenever we hear about SP is What is its place, purpose and value in modern health care systems and our answer quite firmly today is in shaping the minds and cultural practices of our students and the healthcare professionals of tomorrow. Just to speak quickly on my experience on that, as a neuroscience student I wasn't afforded a lot of the knowledge, even about neuroscience diseases like dementia, beyond the very biomedical clinical physical symptoms.

SP experience – seeing patients beyond their disease

It was only through my SP experience – I call it an experience because it was a life-altering experience truly for me, where I saw patients beyond their disease where I saw how you can treat patients not just in a biomedical way but in a more holistic way that's more meaningful to them that actually helps them, enables them to move on with their lives in a way that betters them. All of that, to say that students are the future of tomorrow.

We're so thankful that we've had such incredible supporters in Charlotte Onslow-Forde and Nicola Gitsham, the Head of Social Prescribing at NHS England, who will now be joining us today.

Charlotte Osborn-Forde is CEO of the National Academy for Social Prescribing (NASP). She has led partnerships across the arts, health and sports and environment sectors to enhance national and local wellbeing. Charlotte was formerly the CEO of Involve Kent for eleven years and she transformed it into a key health services provider, aiding over 30,000 people annually. She has been a pioneer herself in SP and has expanded the reach regionally from five to over 102 GP practices in Kent and Medway. With 18 years in the voluntary sector Charlotte focuses on volunteer development, mental health and health inequality and she remains dedicated to supporting disadvantaged communities and addressing issues of stigma, poverty and trauma. She also lectures on SP at Kent and Medway Medical School.

Charlotte, speaking from your experience, not just at NASP, but also from your experience at the grassroots level. What is the value of SP and particularly with students? Why should we care about the students?

Charlotte Osborn-Forde

Thanks a lot and hi everyone. Firstly, what an absolute joy to be here today and I'm sure we are all really excited about it being Social Prescribing Day but also Bogdan's amazing introduction and yours as well, Hamaad. You've covered it beautifully, so what I will share is some of my own reflections.

GP engagement pivotal for SP advance and life-changing benefit to patients

Quite how important the approach and the way that clinicians, GPs, doctors and other healthcare professionals approach this has an instrumental influence over whether people and patients engage. I've seen again and again where if the GP feels something is a positive or good idea, that the patient is far more likely to be open to that change and to listen to the GP and to make that often frightening step of moving forward into doing something to change their life. So, I think that clinicians and doctors and GPS are absolutely pivotal to the movement.

In Kent when SP really started to launch and become more mainstream, we found again and again that it was the clinical leaders – whether senior GPs or medical students – who were really driving the movement, really understood it and were able to open the doors to non-clinical community leaders, others in the health sector and patients and those with lived experience.

So for me, the leadership from the clinicians is absolutely key and critical. It's really critical for patients and people to know that that clinicians value this and that they see it as part of a healthcare approach or potentially even a broadened medical approach.

SP ‘What Matters Most to the Person’ transforming medical approach

Lastly, I think Bogdan has really touched on it. I see this as a genuinely radical and transformational step forward. Because what you're doing with this shifting of the movement is you're actually really looking at what it means to offer clinical and medical services and you're broadening and opening that beyond its traditional remit of as Bogdan called it ‘bones and muscles’ and all of that, to this more holistic whole person approach. And through this mechanism and terminology of SP, actually all that brings in terms of asking What Matters to the Person, what's important in their lives, and looking at all of the things that keep us well, it's genuinely transforming the whole medical approach.

I think that's why it's really caught the imagination of people both in the medical sector and some of the people who have been leading medicine for years and some very senior doctors, but also new people coming into medicine, as you describe, really giving them hope and talking to some of the medical students that I've lectured that's really being the approach is it really sets off a light bulb and it can give them hope. So thank you.

CHAT

Dr Bogdan Chiva Giurca Very well said @Charlotte Osborn-Forde - a huge thank you to the NASP which has been absolutely crucial to keeping students involved and enthused especially through the yearly studentships allowing students to get rewarded for their incredible work within their local community!

Hamaad, chair: Brilliant. Thank you so much, Charlotte for joining us.

We are incredibly grateful for the rich experience that you and Nicola bring today.

Nicola Gitsham is the Head of Social Prescribing at NHS England, Over the last 15 years Nicola has led the development several complex national policies and implementation strategies which have delivered personalised care, tackled health inequalities, and supported the roll out of social prescribing across England. Prior to her career leading national programmes for DHSC, DfE and NHSE she led the development of personalised, community-based services for people with learning disabilities and autism as an Occupational Therapist and Director of an NHS Trust.

Hamaad, chair: Nicola, you've of course been such an incredible supporter from the very beginning and actually help support quite a lot of not just the policy but even help mobilizing quite a lot of the support for SP in England as well. So your reflections, your thoughts, why should we involve students and not just when we say students and medical students but also perhaps also from AHP more widely and also perhaps just reflections on how you've seen SP grow.

Nicola: Fantastic. Thank you. Happy Social Prescribing Day. It's a massive privilege to get to speak to you at the start of your career and it's been really fantastic to be able to support the growth of this movement and Bogdan with your leadership, getting it all started in the early days, really fantastic.

SP creating global change, broadening out to include AHP and other professions

I'm also excited to see this broadening out across professions and including AHP and other professions across the world. The reason I think that's really important is: to create any change we all have to have a common understanding of what the problem is we are trying to solve and what good could look like and then we can move together.

Multidisciplinary, multi-agency approach - SP listening to people with lived experience

No one profession can ever do that and of course we can't do it at all unless we listen properly to the experiences of people with lived experience who tell us how to develop that. So it is really important that we get that multidisciplinary, multi-agency approach and work with people with lived experience.

98% of primary care networks provide SP services

It's been a really exciting time since 2019. Obviously, SP was around before then, lots of voluntary sector organisations were practising SP already. But 2019, of course, that's when the NHS committed to rolling out SP across all primary care networks in England. We've now got over 98% of those primary care networks with SP services and that's resulted in over 3,600 additional link workers and over 2.6 million people being referred to SP.

Why NHS brought in SP

The reasons why we brought it in was: One, it's important for people's health. If we don't start with what matters to you, and if we don't use activities that we know are sometimes better than medicine or really good alongside medicine, like the arts, like exercise, like nature, then we're not delivering a holistic approach, we're not managing to support real people. We're all part of a biopsychosocial makeup, so it's really important.

Wider determinants of health

The other reason why it's just so important is that when I listen to link workers, the majority of their referrals are to support people to address those wider determinants of health - housing, poor education, cost of living crisis, fuel poverty, utilities poverty, digital exclusion, loneliness, social isolation. They're the big issues that people come for with SP. And so they track completely through health inequalities. I've just come out of a session with Sir Michael Marmot, on the health gap, really excellent spelling out the causes of the causes of health inequalities. Of course, SP can't change the housing policy or lots of other things that need to happen, but they can provide a way of getting alongside people and giving people real practical support to tackle some of these health inequalities and inequalities in society that they face. So I think it is critical for all health and care systems, not just in primary care, throughout the whole thing, to understand the sorts of wider determinants that are affecting people's health and to have a way of connecting them to the right support.

As a result, what we're seeing is SP, yes, growing through primary care, but also now developing in secondary care, in children's services, in community services. Because actually, it relieves the time that clinicians might need to take to understand and connect people to social support or other activities that are good for people's health.

More holistic care, improves outcomes

It enables them to deliver a much more holistic healthcare and it improves outcomes. Because people are more likely to engage in healthy activities if they're doing activities that they really love, singing in a dementia choir or something like that, or taking part in a local bushcraft course at one of the nature hubs for people with mental health. We do what we enjoy and it gives us connection, it builds communities. You were very kind when you said 15 years but I think it's a long time ago since I trained originally as an occupational therapist and when I learned about the biopsychosocial approach and personalised care or personalised approaches, it made total sense and I thought when I came out into practice, everybody would think it was total sense.

Find allies to effect change

I would just encourage you all to find allies because you will be shining a light onto things that need to change, that will be uncomfortable for the system to change, and not everyone will want to hear what you've got to say. But your message is critical, and you are the future. So shine bright. Find your allies and help us build the evidence of really transforming health and care and our local communities and people's lives.

CHAT

Dr Bogdan Chiva Giurca: @nicola - huge thanks to you & colleagues at NHS England for believing in us in 2015 and for empowering students - we wouldn’t be here today without you all!

Hamaad, chair: That's absolutely incredible. Well, you've had it there, and actually Nicola, your mentioning Michael Marmot's work on the social determinants of health. It's important to recognize that unfortunately we have a very industrialized system of what we call sick care not truly health care. We admit the sick. We tend to the sick. We care for and heal the sick. And then when we're done, horribly, ironically laughably, we put our patients back out into the very same conditions that cause their sickness in the first place. That's what Sir Michael Marmot says. It's a very cyclical, fragmented, acute care service that doesn't actually do well, not only to the patient, but also to the community that the patient is part of.

Community connection

There's this beautiful quote by Wendell Berry who talks about how the single measurement of health isn't actually an individual person, but it's the community. We've seen that most acted upon during the COVID-19 pandemic, when we saw that even once we're cleaved from our social relationships, actually we can be transmitted and infected. But it's not just about transmission rates and infection rates. It's also about how we're socially connected with one another. That also affects our mental health as well. So it's about how we are bounded with one another and the communities that we live in as well. We recognize that we've lived far too much in a very insular way. It's had very chronic, effects on our health and health conditions as well. We recognize that now and SP touches on the pulse point of all of that and tells us to recognize the issues, and actually to have an active intervention for that. Thank you Nicola and Charlotte for your reflections on that. We're so grateful for your thoughts and for your being here today and for your support more widely as well. Thank you so much for your insights. Because you both referred to the students in the future, we move swiftly on to

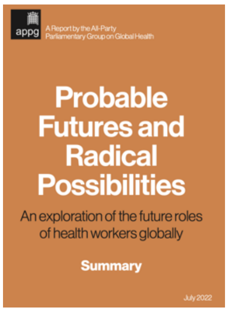
PANEL 2: In conversation with UK-based Social Prescribing Student Champions.

Hamaad, chair: It's my pleasure to be talking to you now of ‘The future of the SP Student Championship Scheme’.

We've talked much about how SP has started within the UK, but we're now very excited to introduce to you I think we like to call it the legacy cohort of the SP Student Champions.hip

Students becoming radical change agents

So if I could invite Kirsty Goodchild, Naabil Khan and Alexander Tan. We'll be talking about what the SP student Championships scheme is, what their role is, and again, pressing upon the importance of students. Just speaking on that, there was a brilliant report published I think over a year ago by the APPG for Global Health and they mentioned how students and this is students not just medical students, students with a capital S, need to become radical change agents. In this next Panel Discussion we'll be talking about how we want to become those very radical change agents. So thank you so much, all for joining, Kirsty, Naabil and Alexandra,. but firstly to give an introduction so Kirsty Goodchild.



appg A Report by the All-Party Parliamentary Group on Global Health

Probable Futures and Radical Possibilities

An exploration of the future roles of health workers globally

Summary

July 2022

Kirstie Goodchild is the SP Student Champion Evidence Lead. Kirsty is a University of Cambridge graduate with a first-class degree in biological natural sciences, psychology, neuroscience and behaviour, in particular. She's also a postgraduate student in occupational therapy at the University of East Anglia. Thank you, Kirsty, for joining today.

Hamaad, chair I guess to first start off, Kirsty, I'll pose this question to you. What is your role as a SP Student Champion, particularly also as evidence lead? And why is it important? We're talking about radical change agents and the need to have SP/

Kirstie Thanks, Hamaad. I have been involved with the champion scheme for the last two years. My background is occupational therapy (OT) so I’m able to talk about the importance of SP from an Allied Health Professional (AHP) perspective. My profession aligns a lot with the principles of SP and that is because as an OT we take a holistic approach to health and acknowledge the importance of meaningful activities for wellbeing. However, the demands of our work can sometimes mean it is difficult for us to explore community options for patients to facilitate their access to meaningful activities, which is why SP is so important. Because it provides us in that service that we can use to help us get patients to those activities that we know are so important. More than that, we need to make sure that the health professionals are aware of what SP is and how it can help them as professionals and their patients. And where better to start than the next generation!

As part of my role previously I worked on an evaluation of the SP Student Champion scheme from an AHP perspective. This evaluation study revealed how useful students had found peer learning of SP for their understanding and awareness of SP and confidence practising SP for their future career. The beneficial insight this research brought has inspired me to continue evidencing best practice for SP learning. That is why I have taken on the role of Evidence Lead. I hope the work that I will do as part of this will continue to help raise the profile of SP so that we can support the next generation of professionals and patients to access the fantastic resources that SP brings.

CHAT

Kirstie https://nsuworks.nova.edu/ijahsp/vol22/iss1/19/ A link to the research paper if of interest :-) Goodchild KA, de Iongh A. An Evaluation of a Student Allied Health Professions' Social Prescribing Scheme. The Internet Journal of Allied Health Sciences and Practice. 2023 Dec 15;22(1), Article 19

Hamaad, chair: Thanks so much, Kirsty. You've been part of the Social Assembly Student Championship Scheme previously as well. Any reflections on how you've seen the SP Student Championship scheme evolve, perhaps also what was the best part, what was the most radicalizing part in terms of your education, and also practice, what it revealed to you and how it helped make things clearer.

Kirstie The former Champions Scheme involved finding champions from universities across the country. The idea was that each university would have a student representative, a champion who would talk about the scheme to their students, to facilitate peer learning. The initial intention for medical students only. We realized quickly that not only medical students needed that peer learning, so the scheme evolved initially by expanding into AHP, nursing and midwifery. We found at that point that we were getting interest from lots of other disciplines, psychologists, PhD students. Lots of students were getting in touch and asking for more information. When we did our more recent evaluation, we realised that the curriculums had actually improved and a lot of universities now didn't really need the champion there because they had recognized the importance of SP and were now teaching it themselves.

I feel the scheme played some role in promoting that. It has now evolved to involve a smaller team, who are all here today, for us to do some more nationwide policy implementation and to continue this message about sharing the importance of SP for students. It has evolved from a widespread diffuse scale of lots of people making smaller impacts, to a smaller team where we will hopefully be making bigger impacts and bigger level change to continue this upward growth in sharing SP knowledge.

Hamaad, chair: Brilliant, thank you. There was the paper written by Dr. Bogdan and others on the call with the statistic that over 93% of healthcare students didn't know what SP was as its terminology and that language was so very far foreign to the minds of the young healthcare students. This was back in 2016 and to say that now we have incorporated and implanted SP teaching, it's not just SP teaching, it's a more holistic way of valuing our patients and shows the importance and power of students and grassroots movements. But thank you so much, Kirsty, for that.

And moving on, Naabil, to talk to you about your role. You are the Global Lead – that's quite a hefty title to give to anyone. But you've also historically been involved in the SP Student

Championship Scheme. It will be lovely to hear about your previous experience and now this new role that you're taking and why it's important to have a global role.

Naabil Khan, SP Student Champion Global Lead

Naabil is an award-winning medical student. She is recognized for her contributions to both healthcare and advocacy. She's the creator for the podcast, Very Junior Doctors, and the founder of the website Skin for All. Naabil demonstrates a commitment to amplifying diverse voices and promoting inclusivity in medicine. She has a passion for global health, which underscores her desire to create more inclusive and diverse healthcare landscape. Worldwide, she's had representation and diversity showcased in media outlets such as the BBC, the *Independent*, the UK Aid and AM. She's also got upcoming appearances on platforms like *The Doctor BMA* and Expose, which further solidifies her influence, in shaping healthcare discourse.

Naabil

First of all, a huge thank you for the amazing introductions and to all the speakers beforehand for introducing social prescription in such a brilliant inspiring way.

I am in my third year as a medical student, actually from the same university as Bogdan, Exeter University, so that's always a privilege. Yes, the Student Champion Global Lead. is quite a hefty title, but I take it more like an amazing opportunity to collaborate with international students, international professionals.

SP – a universal language

It's been said that SP should have a universal language in order for us to collaborate effectively and promote SP practices of different spaces. I am excited to be a part of that.

Medical teaching to include human life as well as human body

I joined SP in my first year of university because it was an opportunity that came about where I thought to myself, medicine is brilliant, medicine provides so much information and so much knowledge about the human body, let's start thinking about human life instead and thinking about the things outside of the signs, outside of the clinical practice. Let's start thinking holistically.

I think it so important that students from very early in their academic careers get involved in projects and opportunities like this, because it primes them to think holistically as they continue in their academic career and then subsequently their professional career. It is really important that SP is advocated for and includes as many students as possible in terms of what it promotes.

For me it was an amazing opportunity that I got to be a part of in my first year and that included creating a few fun videos about SP that were shared by NHS England on Twitter. That was really exciting, to get that recognition about the importance of SP.

I found in my first year as well there were so many students who were interested in the project and in the actual network itself. They thought about social prescription. They didn't have a formal name for it though, so it is something that people are thinking about - especially students – because SP applies to all of us. It's about human life. We all have different lifestyles.

CHAT

Kirstie Goodchild: A phrase you sometimes see in an OT's office is "medicine adds days to life, OT adds life to days". I think this describes SP well too and reflects Naabil's speech well. **Naabil Khan** :❤️ **Rona Topaz** ❤️ **Dr Bogdan Chiva Giurca** ❤️ **Tan, Alexandra** ❤️

Inclusivity of SP

We all have different ways of managing things and SP encapsulates all of that and it's catered for people from different ethnicities, from different backgrounds, from different socio-economic classes. It's an amazing opportunity for you to really explore the complexity of human life alongside medicine as well.

It has been a huge privilege being a part of it and then continuing to be a part of it, sharing those insights, sharing those ideas with an international platform, as well as getting insights and ideas from other international students and professionals will be incredibly rewarding and I think it will really, as Kirsty said brilliantly, push SP to another level where it will just become normalized. We won't start thinking of this as a new scheme, this is a new way of thinking about medicine. This is just medicine, not only are we talking about the body, but we're talking about life as well.

Hamaad, chair: No, quite brilliant. I'm so glad you mentioned the concept of life because I have been thinking about this for quite a while.

You're about to meet your first patient' – a cadaver

The very first medical experience that I had in my clinical career was with a patient. Actually my first patient was a cadaver. It was a dead human body. I remember how the anatomist said quite solemnly, 'You're about to meet your first patient' and all of us students were so very excited. Then we stood and leaned over this very dead body and we were focusing our clinical gaze on the anatomy and for the next months and weeks - every week – we would pinch and cloak deeper anatomy and pull out the membranes.

Clinical biomedical gaze losing sight of patient overall – need to look beyond limbs to life

We abstract ourselves from what we were really looking at and what the patient actually meant. I realized that this is how we are as medical students, and also as healthcare students, unfortunately, we're primed and prepped to have a very clinical biomedical gaze and it helps us unfortunately lose sight of the patient overall. I've realized that how we have to look beyond the limbs and look at the life as you say, quite brilliantly. Thank you so much for that reflection and so exciting to have you as our Global Lead.

Finally, and definitely not the least, we have Alexander Tan. Alexandra is the Communications lead. And this is for social media and communications more widely. Alexandra, it's so brilliant to have you on. You have such an incredible experience and introduction with SP because you were a student of the SP module at Imperial. It will be really lovely to hear you speak on what your experience was with that and how that teaching changed your conceptualisation of your role as a future doctor and also now as your role in the SP Student Championships.

Alexandra Tan is our Student Champion Social Media Lead. She is a fifth-year medical student at Imperial College London, a rising force I must say in health care advocacy and innovation. She's pursuing her medical degree and has had a distinction for medical sciences in 2021. She was highly commended for Community Action project in 2022 and got a merit award in the same year. She equally has a profound interest in women's health, oncology, surgery, med and surgical tech and digital health. She's committed to reshaping healthcare through interdisciplinary collaboration and technological advancement.

Alexandra Thank you so much to Veronica and you for organizing this. It's so nice to see so much enthusiasm for SP. I am currently fifth year out of six years of medical school at Imperial So I'm almost there.

SP as third-year medical student option

I first heard about SP in my third year. During our GP placement rotations, we were given the option of choosing an extra module. We were given a long list of options, we had to rank them and I came across SP there. I had no idea what it was. I never heard of it, but it sounded interesting, so I ranked it as my first choice. I got it and I'm really thankful for this.

I've really enjoyed the module. Firstly, Bogdan and Hamaad, your passion came across so well to the students and you both were so proactive in trying to get us involved, which really made a difference.

SP made the difference when doctors too busy to teach

A lot of medical students can relate to the fact that sometimes you're chopped on a hospital ward. It's busy. Doctors don't really bother to speak to you or teach you sometimes just because they are so busy. So it really made a difference how proactive both of you were. I remember during the module we went across the need for SP, why it's important, how it works in practice, and it really changed the way I looked at medicine. It also made me question a lot of the things that we were doing – or told to do, even.

Overprescribing

One of the big things we discussed was overprescribing, which I'm sure everyone here is familiar with, but obviously it's a huge problem. More than 10% of medications prescribed in primary care are unnecessary and waste around £2 billion per year. This is obviously a huge wasted opportunity cost, when you think about the problems the NHS is already facing with funding.

I saw evidence of this a lot in primary care. In my GP placements, doctors had such a low threshold for prescribing antidepressants and when you think about the overwhelming burden on primary care this isn't a surprise because one appointment is only ten minutes. That's just not enough time to delve into all the different medical, psychological, social, cultural factors that someone's low mood can result on. So it's so much easier to just prescribe something and send the patient away and it's not a GP’s fault, it's a problem intrinsic to how the care system runs.

3-21 SP Screening tool for primary care

Realizing this as part of the module, a group of three students and I developed a SP screening tool to use in primary care. It's called 3-21. There are essentially three questions in twenty seconds and the one is for one Yes. The point of it was to give GPs three quick questions to ask and those questions were,

1) Do you live alone?
2) Have you experienced low mood in the past two months?
3) Are you unhappy with the level of social activity you currently have?

And if the patient answers yes to any one of these questions, then they may benefit from SP. This was basically giving GPs a quick way to screen for whether or not that patient would benefit from SP to improve the provision of holistic care, but also keeping to the time constraints of the appointment. I would love to in future look at doing an audit of this to gather evidence on how it works and how we can improve it.

That was in third year and fast forward almost two years later, the importance and the urgency of SP has only grown.

Role as Comms Lead

In my role as the Comms Lead, which I've only just started this month, I'm very thankful to be involved with it. I've been given the opportunity to participate in the Beyond Pills All-Party Parliamentary Group at the House of Lords to decrease the rate of antidepressant prescribing in the UK.

Advocating for SP integration into mainstream healthcare practice, starting in medical school

I also hope to continue to advocate for SP integration into mainstream health care practices. I do think the best way to do this is to start from integrating this into UK medical school curricula. Hopefully, as a new generation of doctors start to come in, SP becomes more widely recognized, more widely practised as well, and also gains more funding.

Hamaad, chair Brilliant. Thank you so much, Alexandra. There you have it. That is the, UK-based SP Student Championship scheme and it is so incredible that we have Nabil, Kirsty and Alexandra as part of this legacy cohort to establish the hard gained successes that we now have across the healthcare curricula in the UK, but also for moving forward and looking beyond and wider the horizons. still

Students changing clinical practice, introducing learning points, value to future practice

It's quite important that even when Alexandra you talked about how it was a student form of changing clinical practice. You created a screening tool. Again, we're impressing upon the importance of students changing clinical practice, the value of current healthcare students to future clinical practice.

We impose this imposter syndrome upon ourselves sometimes that we're just here to learn, but actually you introduced a lot of SP learning points to a lot of current GPs. GPs, as you say, unfortunately in this country don't have quite a lot of time. There's a brilliant quote in Dr Gavin Francis's books who talks about how GPs constantly live on a knife edge. They have ten minutes to interpret a lifetime of illness and disease. Of course, they're going to get it wrong. Of course, it's going to be pitfalls and caveats. Of course, it's never going to meet the complete sense of healing that the patient is actually searching for.

Clinical gaze and interpersonal gaze – life and limb

That is why SP and vitally, the role of a SP link worker, is so important, so you never lose sight of that patient as a whole. You still have the clinical gaze but you also have the interpersonal gaze, bringing on looking at the life of the patient, but also the limbs of the patient, as Nabil mentioned, quite beautifully.

Thank you all so much.

PANEL 3 : In conversation with International Social Prescribing Student Champions

Hamaad, chair: Now we move on to talk about Global SP. It's been a pleasure and the best part of my job at NASP to be looking at how SP has diffused across different healthcare systems, most importantly, across campuses around the world. I'm delighted to be joined now talking about international SP student collective schemes with Abbey Deguara from Australia, Maddie Maier from the USA and Le-Tien Duong from Canada.

The international SP effort is so incredible. I think it's also more vital to talk about the differences in the way in which each country has picked up their advocating for SP towards the future generation of health care students.

I'll go to you first Abby, because you're joining us from down under in Australia at some ghastly hour - thank you so much for joining us.

Abbey Deguara, Co-lead for the AMSA Social Prescribing Student Collective in Australia, is a fourth-year medical student at James Cook University in Queensland. Abbey's academic achievements include being Dux of College and receiving the Father Bucas Award for excellence. She is also a recipient of the ADF Long Tan Leadership and Teamwork Award and has been nominated for the 7News Young Achiever Award.

Abbey I was going to say good morning, but I guess it's good evening for you guys. It's 4 am, so my voice might sound a little rusty, but I guess I'll have an accent so that's fine. I'm a fourth-year medical student, based in a regional university here in Australia.

I'm the Co-Lead for the AMSA SP Student Collective. We're a branch of the Australian and Medical Students Association. We represent over 18,000 medical students around Australia. We're jan interest group from that. In terms of members, we don't r have specific members for our committee. We just represent all of Australian medical students as a whole.

AMSA SP Collective foundation policy, 2021

We were founded in 2021 after a policy was written under AMSA and everyone was so passionate that had written the policy that they wanted to create this group and we were supported to do that, which is really exciting.

Creating mentorships, between students and GPs, and students and academic researchers

The work that we're doing this year, mainly, we haven't finalized anything yet, but we've decided to work out creating mentorships between students and GPs and also between students and academics, people who are doing research in the SP field, because those are the two main things that medical students are interested in while they're still at university.

Goal to raise awareness to GPs, educating and advocating one SP student at a time

Unfortunately, in Australia a lot of GPs don't even know about SP. So it is hard to gain resources and actually have doctors who are practising in order to meet the mentorship requirements. But that's our main goal this year; and hopefully we can just focus on educating and advocating SP just one student at a time. This is our main goal.

Proposal to include SP in medical curricula

Of course, we would like to advocate for its inclusion in the medical curricula That's a bit of a difficult task, but we'll try. We're currently going to drop a medical curriculum proposal and we'll be sending that through to a couple of more holistic universities and we'll see how we go with that.

Hamaad, chair: It requires a lot of elbow grease as I say, just pushing things inside and getting your seat at the table or rather putting a chair at the table. I think it's so very interesting that you guys in Australia have focused on not doing what we did in the UK, which is getting everything in the education curriculum and nationalizing the learning for SP.

You've actually gone in a very different way and I think it's quite the most intriguing to educate that singular person in SP during experiential way so that they're in the community or they have access to a SP evidence researcher and an academic to see the pitfalls caveats, the leading edge information that's coming out in support of SP.

Was there a particular way or thought process that led you to that?

Abby What led us to that is, we do have a very small group of people who are interested. So it's hard to push for a big group project because we're just not gonna have people on board. It's probably the same everywhere.

SP Engagement very small in primary healthcare, greater interest from researchers

Engagement is especially small from medical students. So I guess we just wanted to think of the butterfly effect of just one student at a time and seeing how their attitudes change and progress with the mentorship programme and then maybe we can scale it up from there and see how we go. But SP isn't very big in Australia yet, especially within the medical community. It's a lot bigger in the research community, but it hasn't come to primary health care yet. So we would like to first engage GPs and students to get the discussion started in the primary health care field because it's not there yet.

Hamaad. chair I think it's such an inspiring way. I think it also speaks to how we've heard from speakers like Nicola and Charlotte and Bogdan talking about how SP is actually giving language to what's already out there. We're certain that SP is happening in Its natural habitats across communities in Australia. It's just you don't have that language, that framework, that recognition for you to actually say that this is what SP is. This is why it's important. Let's galvanize our efforts towards this and create an intervention after this. That's all the more reason why we do what we do and what you do and the incredible work the AMSA SP Student Collective is doing. So, thank you so much and also thank you so much for joining us. At 4 am – we really appreciate that and thank you for your insights.

Abby Thank you so much for having me.

CHAT

meron enyew: Thank you @Abbey This is also a problem in Ethiopia too. Which we have a limited knowledge about social prescription.

Veronica: Abby, your perspective is of such interest. You may like to contact Caroline Gibson at Green Scripts, the SP, dementia-friendly community at Ballarat in Victoria. Here is a link to my Nature and Heritage for Brain Health SP webinar . Green Scripts website links to *the Royal Australian College of General Practitioners (*based in East Melbourne, Victoria, and has an office in Brisbane, Queensland*) RACGP recommends that social prescribing be incorporated into routine healthcare in Australia. It is reported by the RACGP that 70% of GPs believe referring patients to community activities, groups or services helps to improve health outcomes, but most do not have links with such services. Incorporating "Green Scripts" into primary care to address physical, mental health and social care needs of people living with dementia and their support person(s) is a practical way and healthy demonstration of a dementia friendly community in action.*

A new Australian social prescribing study for dementia has been announced by the University of New South Wales's Centre for Healthy Brain Ageing,

Hamaad, chair: Thank you, Abby.

Moving swiftly on: Maddie, you've done incredible work in the US. I think it's very intriguing in the US you always outdo us here in the UK in the worst possible way, might I add. We do do over prescribing and it's unfortunate that we've had a damning report saying that we've overprescribed - 10% of all medicines are unnecessary £2 billion, as Alexandra said, is wasted every year on unnecessary prescriptions. We land one in five patients in hospitals not because of their illnesses but because of the medications that we gave them in essence by prescribing ill health.

But I was most shocked to read that 70% of Americans now are on prescription drugs, which is quite extraordinary. I think that underscores the importance of the student work that you've been doing. I just wanted to put that as the context, and the cultural context that the our US counterparts are living in, to shine the importance of the work that the US SP Student Collective is doing and also the Harvard Undergraduate Initiative for Social Prescribing. Maddie I'd like to invite you to speak on your experiences.

Maddie Maier founded and chairs the US Social Prescribing Student Collective, encouraging student engagement in social prescribing efforts nationwide. She is actively involved in initiatives promoting social prescribing and community well-being. As an undergraduate researcher in the Wagers Lab, she contributes to research projects. Madeline leads the Harvard Undergraduate Initiative of Students for Social Prescribing, advocating for its integration into Harvard's activities.

Maddie Thank you, Hamaad. This is definitely an increasingly scary time that we're living in here in the US and I think it makes our mission to really establish SP in the US in whatever way we can that much more necessary at this moment.

National Student Collective and individual school chapters

I am the chair of the US Social Prescribing Student Collective; and within that I've also founded a Harvard University chapter of this SP national student movement. We have the national branch and then under the national organization we also have chapters at each school. We actually learned a lot from the Canadian Student Collective. Our model is very similar and I'd like to thank Le-Tien and Caitlin Muhl so very much. They really helped us when we were setting this up.

Aim to help students found their own SP clubs

The overall goal of our student scheme is to reach universities and colleges and even some high schools across the US and help these students at each school found their own SP clubs. Like the one we found it at Harvard, we recruit students and then they found their own act at their respective schools; and as the teams during this chat we've also really wanted to focus on getting the next generation of leaders exposure to SP, which then primes them for actually integrating SP into their future careers.

Recruiting students at each level and various fields of education

Since launching last Social Prescribing Day, we've recruited students at various levels of their education. We have a high school student, we've medical students, we have master students, PhD students, and in all different programmes, not just medical school. We've got arts and in college here you don't have to choose a specialty. There's a lot of pre-medical students but also in students that are in different fields as well.

I don't know if the other student leaders have found this, but we found it's quite easy to get students on board with this idea of SP and that the social determinants of health matter. I think our generation is so poised to see health in this holistic way.

How to harness student energy to establish SP into the US system

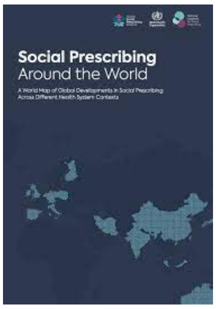
But our task has become How do we harness this energy and direct it toward the specific goal of really establishing SP and creating this robust system in the US. Because we have so many different students involved, each of the clubs have their own goals, their own ambitions, which is really dependent on the goals and ambitions of the people running the club.

That's been really interesting to see what different people's goals are. We have medical students that really want to integrate it into the curriculum. We have students that we see that they really wanted to do hiking trips with people in their club and actually socially prescribed students. It’s been interesting seeing the various ways that you can accomplish the same goal. That's been really rewarding and fun to see what people come up with.

Hamaad, chair

Is US insurance-based health system financial barrier to SP?

I was just going to say that even from our research with the WHO report looking at SP around the world, one of the issues nationally is that of course the US has an insurance-based system, a sort of financial barrier. That's been nationally one of the barriers for implementing SP more widely. But I think that also portrays the value, purpose and importance of the students work because you're leading SP at the grassroots level or you're incorporating embedding yourselves, into SP initiatives that other national leaders are struggling to establish. So it's quite extraordinary to see how the position of a student is removing all of these barriers into just engaging with SP or making these connections as well.



Have you had any challenges so far in your journey as a student leader in the US in SP space?

Abby Just what you mentioned that in the US, we're coming from a place where we have to established SP in this grassroots way. The students are so powerful. We are really in a powerful position. But it is difficult to reach out to all these different students and manage all of their different objectives as a larger organization. I think we're still trying to work through how best to do that. That's definitely been our main challenge so far, but it's still really rewarding and wonderful and people are doing great work.

Hamaad, chair We're all very grateful for the work that you're doing and needing in the US in the student space as well. Thank you so much, Maddy.

Speaking to Le-Tien about the Canadian Social Prescribing Student Collective, you've been in this space for quite a while. You were the co-founders in the initial movement in Canada. How is this SP Student Collective formed in Canada? And what have your insights been overall leading in that space.

Le-Tien Duong Bhaskar, Co-Lead of the Canadian Social Prescribing Student Collective, is a PhD candidate in Health Policy at McMaster University in Hamilton, Ontario, Canada. Her interest in social prescribing began several years ago, when she was exploring ways to connect health and social systems. Since then, Le-Tien has become involved in social prescribing through her work with United Way Halton and Hamilton and her dissertation on health systems transformations through community-led social movements.

Le-Tien Thank you so much for having me. It's so exciting to hear about the growth of SP across the world. The Canadian SP Student Collective started almost two years ago, which blows my mind in 2022. Social Prescribing Canada is very different, very much grassroots, where there's just sporadic little practices emerging all across the country. We initially started with three students and I think this is where it really explains a lot about how we've grown. Three students, none of them were medical students, but all of them are passionate about SP. There was myself – I'm a PhD candidate in health policy - my colleague, Caitlin Muhl, who is a PhD candidate in health quality, and Nilou (*Niloufar* Aran) who since moved from the role but she was influential and she was a MSc student studying population health.

When we first met, it was amazing for us because we were all working in our little individual pockets, surrounded by people who didn't know what SP was. It was so amazing and rewarding to be able to talk to people who share the path, same passion as us.

We started up the collective initially based on the model in the UK, I believe around that time there was the global report that was released. What we realized was that SP here in Canada is really all about community. Whatever community you're in, whether it's local community, the student community, the different pockets of disciplines, everybody has a community and that's everything that we're trying to foster and really try to exemplify, and how we were built.

When we first started, we didn't have any barriers for anybody. Well, the only one was that you'd be post-secondary. But we had students from all disciplines, different levels of education. We have quite a few undergraduates, different levels of education. We have quite a few undergrad students. We have master students, we have PhD students, we have medical students, and they're from all over the place and it's been amazing learning from all these different perspectives.

Discussing SP with range of students across the country, learning impact of arts for health

That's one of the things that I'm most grateful for and this opportunity to talk to students across the country and learn about what they know and we can also talk about SP and how it fits into their work. For example, we had quite a few public health students. We have an arts therapist who has always shared insightful comments with us about how arts can be so impactful for health. We have social workers, we have people who are very passionate about this work that may be in fields that some may not have considered.

I believe we might have some business students. Regardless, we have people who are passionate about SP. I think that just goes to show how important SP is here in Canada.

Since 2022 over 300 students have joined our movement. We have quite a few university chapters. I'll double check the numbers, but we have quite a few university students.

Five Canadian SP Student Collective working groups

Canada is a really big country. Being able to navigate that has been particularly challenging. We have five working groups who work on a national level:

- Policy Working Group creates policy briefing
- Research Working Group recently published a protocol for a scoping review that they're going to do
- Knowledge Translation Working Group goes out to different universities and talks about what SP looks like.
- Practice Working Group, because we recognize that students have always been integral to the SP world, so people who are already doing the work can have an opportunity to talk to each other
- Medicine Working Group similar to the champions model, where we have medical students working together. I believe they're setting up something similar, with a champion at each medical school.

Led by full-time students, all volunteers, without funding

Everything has been pretty much led by students' initiatives and for this amazing work I have to credit our students because we are completely volunteer run. We have no funding. All these students are full-time students and they have done absolutely phenomenal work.

University chapters

We have university chapters as well. One chapter in a university in Ontario, Brock University has implemented SP on this, which is the first of its kind in Canada. They did that purely out of their own passion for the work.

First SP student conference 2023

We have other students who have started conferences. The first student conference, which was amazing, led by our university of Toronto colleagues.

Just so many things, we are really getting started as we're working through all of this, but I am so excited to see how we've grown and how we will continue to grow moving forward.

Hamaad, chair It genuinely is so inspiring to hear about the efforts. I want to press on that point further. You yourself, Le-Tien said that you're so impressed by the student involvement. What do you think it is that makes students attracted to the cause of SP, to the cause of volunteering their time. Like you said, it they've given considerable effort and to brilliant effect because the Canadian SP Student Collective is doing incredible work What is it that's making students attracted to this cause?

Le-Tien I think it's because it makes so much sense. Every time we try to talk to a student who tries who joins our movement, SP always makes sense to them, Even for people who are not medical students:

- Social Determines of Health really resonate with students
- It's also that sense of community. The students love learning from each other.

Whenever we ask them: What more do you want? They just want to talk to each other across the country. We have that national community we help foster community on campuses as well to again help them help each other.

A more connected future

A lot of the students are really passionate about making their campuses better for their colleagues and peers. I think they're all envisioning a future where we're more connected We're working together more and I think that's what's really driving them. Honestly, it's amazing to see.

Hamaad, chair Brilliant. Thank you so much, Le-Tien, for that.

Sharing knowledge of SP practice

I think what I'll end on on this panel about the international SP Student championships team is that it isn't just, as we've heard about how SP is happening from the students in grassroots level, it's how we're sharing our knowledge of these models and of these practices. The US learned from Canada, Canada from the UK, Australia has been learning from everyone and we are in what I call the embryonic stages of the international student movement for SP.

Empowered students as radical health and wellbeing changemakers - leaders of tomorrow

It's so empowering to see students take on the challenge of becoming the future leaders of tomorrow, of becoming the radical change agents of the necessary change that is needed in our modern health care systems.

Congratulations and a huge thank you to our student leaders for all the work that they do continuously. It's all in the service of not just the patients, but also improving our health service, improving the wellbeing for all as well. It's a truly important social justice cause that I'm forever proud of being part of.

I'm grateful for this international community as well.

PANEL DISCUSSION – chaired by Hamaad Khan

Introducing SP to your country

Professor Ruth Matteus Barr, University of Applied Arts, Vienna: I am very happy to be here and to listen what you're doing. I'm from Austria and Vienna. I think Austria is very far away from social prescribing. I think we are on the start and I'm very happy to be able to learn from you. I also think it's great to have something like a network like this to learn from each other.

I'm very engaged in arts and dementia. Veronica was our expert supervisor in the project, which has now finished. I'm engaged in this topic, but I'm also working with people with multiple impairments. We will present this at the European League of the Institutes of the Arts ELIA Biennial Conference in Milan. I don't know if any of you are going there from ELIA. We are engaged there and I'm a multi modal art therapist, a professor at the University of Applied Arts in Vienna

Hamaad, chair Yeah, it's, so incredible to hear from your Ruth and for bringing your, perspective, in Austria. We have such incredible developments in Austria as well.

CHAT

Veronica Franklin Gould Ruth lovely to see you. You do incredible work. I wonder whether there was a response to Edith's Social Prescribing White Paper for Austria? (Edith Wolf Peretz of Arts and Health Austria, invited me to write on social prescribing for an Austrian White Paper and addresses SP in Arts and Health Austria in an international context.),

Anna Formosa: In Malta we are same, still very early stages, so it is fantastic to hear all of your experiences. Myself and some others together with Arts Council Malta just delivered some workshops and a forum to start the conversation. As it were, I studied applied drama in 2004 at University at Exeter as well 🙂 I currently teach applied drama as part of other courses at University of Malta, so introducing SP through students associations sounds great. **Hamaad, @HamaadAKhan**: ❤️

meron enyew : I am so delighted and motivated to be a part of it. And my question is that. Since am in Ethiopia which social prescription is not known. How can social prescription established from your experience?

Hamaad, chair I think the question that you're posing is almost similar to the question that we have from Meron in Ethiopia, which is so incredible to hear, Meron, talking about, how SP could be established. Maybe some of our student leaders can speak on that.

Kirstie, I know you've also had some historical experience in the Student Championships game as well. Maddie, you've led the US movement and Le-Tien in Canada. How would you suggest what you think is perhaps the most golden nugget for establishing a movement like SP from the ground up.

Kirstie, UK Student Evidence Lead, opening up SP in Gibraltar I'm happy to give some thoughts based on my elective placement. I do think networking is quite a big part of this. For my occupational therapy, elective I was in Gibraltar which is a British overseas territory at the bottom of Spain. They don't have SP there even though the healthcare model is based on the NHS. So it was something that I was quite keen to talk about to healthcare professionals whilst I was there.

Hospital presentation, invited to present Conference, liasing with MP to establish SP

I shared how it works in the UK in a presentation in the hospital. That was positively received and I was invited to a conference that was happening in the country about Learning Disability Support and I presented the same speech there and the member from the government who was involved in healthcare was present and he passed on his email address and we've been in contact to try and get SP as more of a formal service In place in the country. The way I started to initiate that was through being passionate, sharing, and case of the examples of how it works in similar countries.

For Ethiopia, suggest researching how other African countries develop SP

If you're thinking about Ethiopia specifically, it might be worth looking at if SP is active in any of African countries and using those as case studies and maybe just educating from a hospital level or healthcare level and trying to spread that message further. It was much easier in Gibraltar because it's a very small territory. That would be my advice.

Hamaad, chair Thank you, Kirstie. Le-Tien have any thoughts from your experience how to establish a movement like SP?

Le-Tien, Canada I think because SP is still not very widespread in Canada, one thing that we really embrace is this Come As You Are philosophy. If you don't know a lot about SP, please join, chat with us because all of our members are super passionate about the cause. They may not be SP experts yet, but I will argue in their own way that they are.

Embracing SP as a learning journey

It's really a learning experience for us. I will also say that networking is important. We are very, we work very closely with the Canadian Institute for Social Prescribing, CISP, which is the Canadian version of NASP, I imagine. Whenever their opportunities come to us, we share it with all of our members. I'm a strong believer in learning by doing, so even if someone doesn't know about SP, if someone asks for a new presentation, I will invite all our members to see who's interested and then through learning and developing a presentation, for example, you'll definitely learn more about SP. Embracing that this is a learning journey for everybody is something that's really important.

Hamaad, chair Brilliant. Thank you so much. Maddie, any US insights and perspectives on how you establish that movement and how someone else in your shoes and your position could perhaps establish a SP movement?

Maddie, USA I think as Le-Tien said we relied super heavily on the founder of SP U.S.A, Dan Morse, and we really utilized his connections, especially for the Harvard chapter,

Setting up SP internships, through tangential Network

We actually set up almost mini internships for students to get exposed to SP. We used that network of people to draw from. These are people that are not necessarily doing what they would necessarily call SP. Dan did a really good job of including everyone that was within the breadth of SP, even if they didn't call it that themselves. So being super inclusive of everyone that's almost tangential and educating about SP along the way, I think has done wonders for the SP network in the US.

Hamaad, chair Brilliant. Thank you so much, Maddie.

CHAT meron enyew Thank you 👏 all for sharing hope Ethiopia will be on of social prescriber country. 🙏

There was just one final question, which is talking about the funding model for championing,

CHAT Rowena Richie :Can you please speak to the funding model that you're championing?

but I think that Le-Tien mentioned it there saying there is no funds. We're running on the muscular energy of volunteering and volunteerships and how incredible it is even here in the UK Student SP Championship Scheme. and though there are some studentships, there are far more students that are actually being involved in the scheme and how incredible it is that we're attracting the future generation of healthcare workers.

Hope for the future, SP looking beyond limbs, into the lives of and for our patients

I would like to end on the message of Hope. Even as a future healthcare worker, there's much to be said about our future home and our future occupation, the health service and how it's underfunded and overwhelmed. It's stuck in this polycrisis. But I see SP and aspects of SP as the way forward, as the necessary way forward. It is about instilling a sense of wellbeing and resilience, a holistic healing that is not just meaningful to the patient, but in a way that is life affirming.

We talked much about life and I think that's what it is. It's about redesigning our clinical gaze to look beyond limbs and look into the lives of our patients to help construct meaningful lives for our patients. And in return we're constructing a meaningful vocation for ourselves across the healthcare as doctors, as AHPs, as occupational therapists, speech and language therapists. It's about asking What Matters to the patient.

It's so inspiriting to see the SP student champions across the world, here in the UK, but also in the US, Canada, Australia, and beyond as well. I just want to say thank you on behalf of everyone for your interest as well, for joining this webinar. it's just incredible to be celebrating this and talking about this poignantly on Social Prescribing Day.

So as I end on that, I'd like to thank Veronica for her efforts in constructing this and helping organize this webinar and forever creating a good space for critical and insightful discussions.

Thank you so much, everyone.

Veronica Franklin Gould, host Thank you, Hamad, for masterminding this meeting and your radio experience has led you to be the perfect interviewer. We've covered such a range. Thank you to all the speakers. it's been such an honor to hear from you all, from Canada, America and Australia, to hear from around the UK. You are so impressive, helping to enhance life the world over. We have much to learn from you. Thank you for sharing your insights on Social Prescribing Day.

We look forward to studying your *7 Years On* report. So thank you all very much.

Hamaad, your volunteering, the first of a pioneering series of SP Student Champions for Arts 4 Dementia, set a magnificent precedent, which I highly recommend for mutual learning and support, both for the social prescription and funding. With regard to Rowena's question on funding, NASP's 2020-21 pilot *Thriving Communities* model, which we laid out in our report *A.R.T.S. for Brain Health: Social Prescribing transforming the diagnostic narrative for Dementia: From Despair to Desire*, (2021) is an ideal model in that the prescription – ie the cultural organisation is the lead partner in a collaboration that must involve a primary care social prescriber and it helps too to involve the local authority and ethnic/faith community and university for SP and cultural students to engage with the prescription participants and assist evaluation. Such a collaboration should raise awareness to all parties, populate SP programmes and attract sustainable funding upon which local authorities can pride themselves.

Warmest thanks to you to all our speakers, for your highly valued leadership of the life-enhancing SP movement, which offers unprecedented opportunities to preserve brain health, override loneliness and nurture resilience in the community for longer. Thank you Bogdan, and Hamaad, how magnificently you have organised and run today's Conversation – your joint vision is inspirational.

CHAT

Charlotte Osborn-Forde :This has been an incredibly inspiring session, thank you so much who has spoken. Despite the health challenges we all know about, clearly there is a case for optimism with the leadership and vision shown today. NASP is keen to support and advocate for the work to further empower you! And of course thanks to Bogdan and Hamaad who have made this such a powerful session and to Veronica too of course! Very excited to continue this conversation.

Dulcie Alexander Arts Council England Thank you

Hamaad, @HamaadAKhan Thank you everyone for joining **Le-Tien Bhaskar** Thank you for having us!

Anna Formosa Thank you so much for this insightful webinar!

Gillian Gourlay :Many thanks

Kirstie Goodchild Thank you goodbye :-)

Our next Greengross Arts for Brain Health Changemakers Conversation will focus on remarkable trauma-informed cultural programmes for refugees and migrants on World Refugee Day, Thursday 20 June 2024.

CONVERSATION **5**

World Refugee Day Conversation, Thursday 20 June 2024

Greengross Global Arts for Brain Health Changemakers Conversation 5

World Refugee Day Conversation (Thursday 20 June 2024)

THE CONVERSATION

HOST : **Veronica Franklin Gould,** President, Arts 4 Dementia

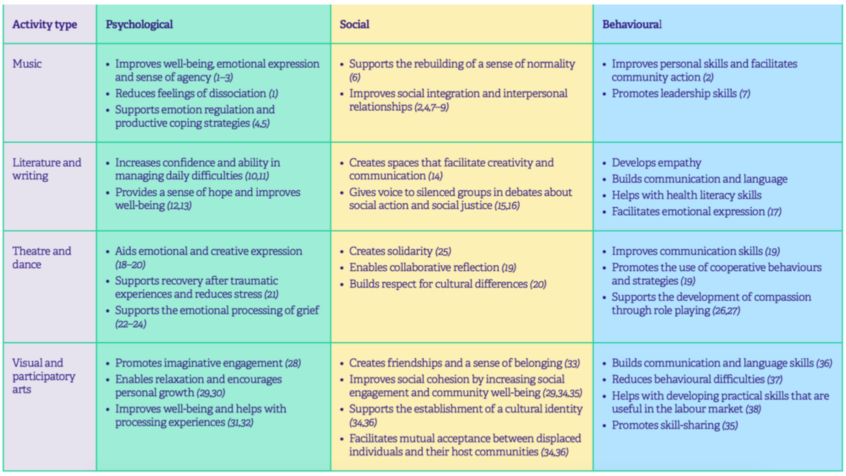
Today, World Refugee Day, it is wonderful to welcome you all – from Austria, Cameroon, Canada, Egypt, France, Germany, Ireland, Jordan, Nepal, Nigeria, Qatar, Romania, Spain, the USA and the United Kingdom - to this special Greengross Arts for Brain Health Changemaker Conversation, to raise awareness of the crucial role of participatory arts as rehabilitative support for refugees. I am delighted to find that my London Borough of Wandsworth runs an Arts Festival of Sanctuary – there are Cities of Sanctuary all over the UK.

The UN Refugee Agency (UNHCR) reported at the end of last year, that over 117 million people worldwide were forcibly displaced due to persecution, conflict, violence, human rights violations and events seriously disturbing the public order. Conflicts from Sudan to Gaza and Myanmar are creating new displacement. Last month that figure rose to 120 million.

Over six million are asylum-seekers – that is, they have applied for asylum and await decision as to whether they will be granted refugee status - and over 36 million are living as refugees. UNHCR warns against apathy and inaction.

Our speakers today, who all do remarkable work, explain how they use arts for people facing the trauma of displacement, the after-effects of torture and more, from such countries as Bosnia-Hercegovina, Georgia, Columbia, Israel and Palestine, Ireland, Sierra Leone, Sudan, Iran, Sri Lanka, Congo, Eritrea, Nigeria, Pakistan, Afghanistan Tajikistan. Their work aims to prevent retraumatisation in a strange country.

They bring vital help at all stages of the refugee journey, either locally in camps or from arrival to longer term. How vital that support is in terms of psychological behavioural impact



Activity type	Psychological	Social	Behavioural
Music	• Improves well-being, emotional expression and sense of agency *(1–3)* • Reduces feelings of dissociation *(1)* • Supports emotion regulation and productive coping strategies *(4,5)*	• Supports the rebuilding of a sense of normality *(6)* • Improves social integration and interpersonal relationships *(2,4,7–9)*	• Improves personal skills and facilitates community action *(2)* • Promotes leadership skills *(7)*
Literature and writing	• Increases confidence and ability in managing daily difficulties *(10,11)* • Provides a sense of hope and improves well-being *(12,13)*	• Creates spaces that facilitate creativity and communication *(14)* • Gives voice to silenced groups in debates about social action and social justice *(15,16)*	• Develops empathy • Builds communication and language • Helps with health literacy skills • Facilitates emotional expression *(17)*
Theatre and dance	• Aids emotional and creative expression *(18–20)* • Supports recovery after traumatic experiences and reduces stress *(21)* • Supports the emotional processing of grief *(22–24)*	• Creates solidarity *(25)* • Enables collaborative reflection *(19)* • Builds respect for cultural differences *(20)*	• Improves communication skills *(19)* • Promotes the use of cooperative behaviours and strategies *(19)* • Supports the development of compassion through role playing *(26,27)*
Visual and participatory arts	• Promotes imaginative engagement *(28)* • Enables relaxation and encourages personal growth *(29,30)* • Improves well-being and helps with processing experiences *(31,32)*	• Creates friendships and a sense of belonging *(33)* • Improves social cohesion by increasing social engagement and community well-being *(29,34,35)* • Supports the establishment of a cultural identity *(34,36)* • Facilitates mutual acceptance between displaced individuals and their host communities *(34,36)*	• Builds communication and language skills *(36)* • Reduces behavioural difficulties *(37)* • Helps with developing practical skills that are useful in the labour market *(38)* • Promotes skill-sharing *(35)*

can be seen on the screen, social and now, thanks to the World Health Organisation (WHO)'s arts and health programme *Supporting the mental well-being of forcibly displaced people*. Christopher Bailey, the WHO Arts and Health Lead, is in Ukraine today but has pre-recorded our opening interview with Cornelius Katona the Royal College of Psychiatrists' lead on Refugee and Asylum Mental Health, and Almir Koldciz, Director of Counterpoints Arts.

You then hear the various ways arts support is offered in detention camps, asylum hostels, hotel accommodation or community centres, university - encouraging refugees to express their thoughts, to connect through storytelling, with or without interpreters. Through writing, participatory arts and drama co-produced performances and physical therapy, refugees are enabled to rebuild confidence, identity and sense of belonging in a safe and welcoming community.

The original idea of these global arts for brain health webinars, inspired by our late patron Baroness Greengross, Co-Chair of the All-Party Parliamentary Group on Dementia, was to raise awareness of the rehabilitative role of culture and creativity for people with early-stage dementia. Dr Hanan Khalil has that experience as a Global Brain Health Institute Atlantic Fellow. But by and large the communities we shall be hearing about embrace natural care for their elders with dementia. Our overall chair is

ALEXANDRA COULTER, Director, National Centre for Creative Health (NCCH). ,

who will introduce the keynote session, after which Professors Cornelius Katona and Rachel Tribe chair two sessions, with a musical interlude in between - The Unknowns', the Hear Me Out refugee band performing 'Hope to Humanity'. Finally, Alexandra chairs PROJEKT ENCOUNTER, the Drama for Refugees partnership between Maria Aberg's PROJEKT EUROPA and University of Kent, whose student involvement ensures legacy. Alex launched the National Centre for Creative Health in 2021. As Director of Arts & Health South-West for fourteen years, she provided the secretariat for the All-Party Parliamentary Group on Arts, Health and Wellbeing and project managed its two-year Inquiry and 2017 *Creative Health* report, the seminal resource to which we all refer. Her Culture Health and Wellbeing International Conferences raise awareness the world over. She also helped set up the Culture Health and Wellbeing Alliance and the Lived Experience Network. Alex, it is an honour to welcome you as chair:

CHAIR **Alexandra Coulter, Director, National Centre for Creative Health**.

Thank you so much, Veronica. I'm absolutely delighted to be here at this event on World Refugee Day and congratulations Veronica because they have a fantastic line-up of speakers. I's very exciting to be able to welcome our first panel, which is pre-recorded because Christopher Bailey of the WHO is in Ukraine today and isn't able to join us in person. We are joined here, but first in the pre-recorded video, by Professor Cornelius Katona who is Medical and Research Director of the Helen Bamber Foundation and the Royal College of Psychiatrists' lead on Refugee and Asylum Mental Health. He is also joined in the video by Almir Koldzic, Director and Co-Founder of Counterpoints Arts.

Professor Cornelius Katona Medical and Research Director of the Helen Bamber Foundation. Royal College of Psychiatrists lead on Refugee and Asylum Mental Health

Welcome everybody on World Refugee Day. I'm Cornelius Katona, I'm a psychiatrist by trade. I'm the Royal College of Psychiatrists' lead on Refugee, Asylum and Mental Health. and I also work as Medical Director at the Helen Bamber Foundation, which is a charity that supports survivors of extreme human cruelty such as torture and human trafficking. It's a real pleasure to be able to speak to Almir Koldzic and to Christopher Bailey today. Almir, can you tell us a bit about the work that you do?

ALMIR KOLDZIC is Director and Co-Founder of Counterpoint Arts.. The main focus of his work so far has been on developing creative strategies and national networks for arts and refugees; building long term collaborations with leading inter/national arts, cultural, advocacy and philanthropic organisations; and curating and producing a wide range of commissions and programmes relating to displacement, diversity and social justice.

Almir Koldzic, Director and Co-Founder, Counterpoints Arts 'Creatively Minded and Refugees'

Of course, thank you, Cornelius. Counterpoints Arts is an arts organization engaging with experiences of displacement and migration. We are based in London, but we work nationally and internationally. Our practice is about developing arts and cultural programmes to do with the experiences of displacement and migration. We have a range of different programmes that include Refugee Week Festival, which is one of the UK's overall biggest festivals engaging with refugees.

Supporting refugee and migrant artist to develop practice in the UK

Lots of our work is about supporting artists from refugee and migrant backgrounds to develop their work and practice in the UK. We work a lot with mainstream and other arts and cultural organizations and communities on programming, commissioning artists and showcasing the voices and stories of refugees and migrants in a whole range of different programmes.

Collaborative impact

I should just also add that literally every aspect of our work is done collaboratively with others and that's a very important aspect of our work that helps us reach a greater impact than we as a small organization would be able to do by ourselves.

Professor Katona Thank you. Christopher, perhaps I could start by asking you what you're going to be doing on World Refugee Day.

CHRISTOPHER BAILEY is WHO Arts and Health Lead, based in Geneva, Switzerland. His programme focuses on the research agenda, community implementation and mobilising the global media to explore, understand and support the health benefits of the arts, in everyday life as well as an instrument in the field. He is also co-director of the Jameel Arts & Health Lab, a collaboration between the WHO, NYU Steinhardt, Community Jameel and CultuRunners, which coordinates and amplifies scientific research into the effectiveness of the arts in improving health and wellbeing, to promote its integration into mainstream healthcare and drive policy implementation across 193 UN member states. Educated at Columbia and Oxford Universities, as well as at the American Academy of Dramatic Arts, before entering Global Health and Philanthropy, Bailey was a professional actor and playwright.

Christopher Bailey, Arts and Health Lead, World Health Organisation.

Well, certainly Cornelius and it's a pleasure to be here. I'm the Arts and Health Lead at the WHO and on World Refugee Day I'm actually going to be in the Ukraine working with community groups, NGOs and the government on the uses of the arts in a health context in a conflict zone and that will include internally displayed people as well. We also have been working quite extensively in refugee situations around the world.

Professor Katona Thank you. There's important commonality there, particularly at this time, which is how organizations like those that you both work with, rise to the occasion when new conflicts arise and people are newly displaced. I wonder if either of you would like to make some comment on that.

Almir Koldciz, Counterpoints Arts I'm happy to start. Basically, the main focus of our work is on supporting and working with artists who are coming from a whole range of different settings, some of them are new to the country, some of them have been around for a while. What we try to do is to respond to their needs and to see how best we can support them in developing their artistic practice.

Of course, it's not always the first need that people need addressed when they come to the UK, because there are all sorts of practical, logistical and other more pressing issues that they need support with. But we are basically there to try and support people to develop their work and to try and develop new networks to start practising their art forms in whatever way they find suitable and possible in this context.

Arts to improve mental health, engaging in various settings.

But also one new element of our work we've been developing over the last few years has been to do with mental health and looking how artistic practice enables people to improve their mental health and to benefit from engaging in arts activities in various settings.

Professor Katona Thank you. Christopher, I wonder if you might respond to that. I'm very much aware of the work that the World Health Organization does, for example, in terms of mental health first aid. I'm just wondering how artistic activity interacts with that; and taking Almir's point, how one prioritizes between those very urgent practical needs on the one hand, and perhaps slightly longer-term thinking in terms of artwork and involving people in more positive things.

Christopher Bailey, W.H.O. Well, indeed. In fact, I've been working with our mental health department at W.H.O. on creating a Refugee and Migrant Mental Health Toolkit, a set of materials for artists to help triage in an emergency situation of any sort. Included in that material are also some guides for self-care as well, because oftentimes artists are not necessarily trained in mental health or emergency response.

To have a clear idea upfront about how they should engage, when they should engage and what to be careful of, not just with the people that they're serving, but with themselves as well, I think there are some basic things that can be done in the first instance to make the situation a little more friendly, a little less frightening to help. But in most of the groups that I work with, they characterize themselves as second responders, not first responders, that when you are in crisis and you have been recently displaced, your main concern is going to be a roof over your head - medical care for yourself and your family, food, clothing, security. Anything else could actually be a triggering distraction.

But once those basic needs are taken care of – you have shelter, you have food, you have security, you have medical attention – that's actually when the enormity of the situation begins to weigh down on you and you begin to reflect on what you've lost and begin to feel the first inklings of anxiety about the uncertainty of what's to come. That's when I think an arts intervention can begin to be useful in a profound way of not only easing some of those concerns, but helping you cope and manage the situation that you're in; and imagining what are the choices for the future.

WHO and Red Noses International in Ukraine

I saw a wonderful example when I was working with Ukrainian refugees in Moldova at the beginning of the war where the children were visibly distressed. They were sullen, they had dark circles under their eyes. They clearly hadn't slept in a long time, or slept well. In that case, I was working with Red Noses International, a group of healthcare clowns. When they began their clowning routines, the children were at first hesitant. They didn't know what to make of it. And when one began to laugh, it gave permission for the other children to begin to laugh; and it began to ripple almost like a viral wave. To see these children who clearly were in distress, suddenly laugh like children again, it was like a rain falling on a desert and the spring flowers immediately blooming in the form of smiles. The mothers began to cry because they hadn't heard that sound in weeks. It was a remarkable event.

Professor Katona That's a wonderful story. Can I come back on that? I'm wondering Almir, how that works in terms of the work you're doing with people who have been displaced very far. Because one thing that I find myself faced with quite often is that it's very difficult to sustain recovery, that people may appear to improve, but when even quite a small new crisis happens – perhaps bad news from home, perhaps some setback in their legal case, working towards sanctuary – then it's as if things are back to where they were a long time ago and it's quite difficult for non-clinicians to deal with that.

Sometimes there are quite serious safeguarding issues that need to be dealt with. How do you and your colleagues deal with that sort of thing.

Almir Koldciz, Counterpoints Arts Absolutely, what you have said also is something we have seen through our experience that healing process is nonlinear. There is no one clear trajectory of people, engaging with an activity or whatever it is and then suddenly improving and that becomes a very clear upward trajectory. Things change all the time.

I think one big issue when we talk about refugees and asylum-seekers is that due to the experiences they've had, they are very likely to have some sort of stress, some sort of anxiety, some sort of trauma that they are bringing with them. Then when they come to a hostile environment like we have currently in the UK, where the system is designed in such a way as to make that whole process even more difficult, that means there's so many potential triggers to make that situation much worse. That's a really challenging context to work in for anyone who wants to support this group.

Refugees five times more likely to develop mental health issues

One of the research findings suggests that refugees are five times more likely to develop mental health issues than, for example, the general UK population because of this context. that I don't think there's one way of responding to this. There is a whole range of things that need to be addressed. Arts certainly can play a role in that, but it cannot be the only the only vehicle and the only means of support for people experiencing these challenges**.**

Professor Katona There's something that you both said which resonates very much for me about how that is difficult for the individual asylum-seekers and refugees concerned, but it's also difficult for the people working with them. I was just wondering about your approaches – I was going perhaps to start with you, Christopher, in terms of the W.H.O. approach to staff support, to helping people who are themselves quite often, certainly in my experience, find it quite difficult to deal with a hostile environment, to deal with people who are not on a linear trajectory.

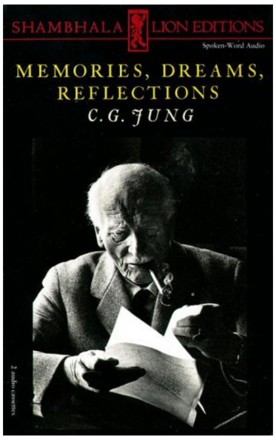
So it's dealing with the clients themselves, but also dealing with the difficulties they face. How can we best support staff in turn to support and work with help the client journey?

Christopher Bailey, W.H.O.

The WHO Refugee and Migrant Health Toolkit

Well, in our case, we've actually developed, as I mentioned, some tools and some training to help people who are doing these sorts of interventions – they can be small things like learning how to use breath to ease anxiety if they feel overwhelmed, encouraging people to talk to colleagues, and not, keep it in. There are a whole series of basic tips that are part of this package that may seem obvious when you read them, but in the moment, your reaction may not allow you to do these practical things. One of the things I've noticed in the most successful programmes is that it's more than just entertaining the refugees.. That does bring relief and escape and connection and it can sometimes **be** very moving. The effects of it can last, more than just the performance itself. We have measures that has actually demonstrated this.

But the most sustained approaches are ones where the groups are taught how to use these expressive practices themselves. So it's more than just a performance or an exhibition. It's actually giving permission and a few tools for people, if they so choose, to actually learn how to express their issues.



One of my touchstone quotes is from Carl Jung (1875-1961) who said *Loneliness is not the absence of people loneliness is the inability to express what matters to you most.*' (Memories, Dreams & Reflections, 1961) If we can give people those tools that can ease that loneliness. Fundamentally one of the core parts of being a human being is the search for meaning and when an acutely negative event happens like displacement, finding a meaning in that can be extremely challenging. But it's also necessary to cope with it and then then eventually thrive. It can be something as simple as, I mentioned the clowns a few minutes ago,

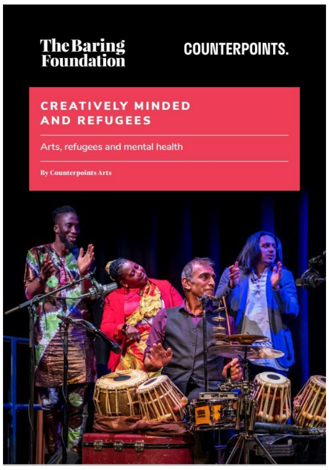
Dealing with uncertainty

Seeing the clowns give out little soap bubble kits to the kids, and just letting them blow bubbles, there was something about that, the delicateness of the bubble, the simple beauty of it, but then it breaks and it's okay. Teaching them how to juggle plastic plates on a stick. At first they couldn't do it and the plate would fall, but it was plastic and it didn't break. In this world of clowning, making a mistake is not tragic, it's funny and then when you get it right, it's a moment of celebration. So actually dealing with the uncertainty and imbalance of the world and gaining mastery over it and, even in failure, coming together and joining in a spirit of good cheer and mutual support was for these kids a tonic.

Professor Katona Maybe another couple of things that that you mentioned that might be worth drawing out, it's not just finding, but expressing the meaning and perhaps it's doing so non-verbally as well as verbally. I wonder Almir. what do you think about that.

Almir Koldciz, Counterpoints Arts Absolutely, so there's a few things that come to mind immediately. One of which is We, for example, also have a programme, called No Direction Home. – That's about comedy, training **up asylum seekers** and refugees to develop the stand-up skills. Then they go on and perform, sometimes alongside very established comedians in all sorts of different venues and we find that comedy, as Christopher was just saying, can be a really empowering tool for coming to terms with and processing all sorts of information and experiences. Of course it's different from people we work with would have been here in this country for a while, so they wouldn't be necessarily facing those very acute crisis points, but they would definitely be facing some crisis points.

Creatively Minded and Refugees



The Baring Foundation

COUNTERPOINTS.

CREATIVELY MINDED AND REFUGEES

Arts, refugees and mental health

By Counterpoints Arts

Last year we developed a report. I believe it's one of the first reports on art, refugees, and mental health in the UK context. We developed it in collaboration with the Baring Foundation, who had been awarding grants for creative activities.to do with mental health since 2020. Last year they invited us to collaborate on developing this report, *Creatively Minded and Refugees*. In that report, we profiled twelve different organizations, case studies that use different art practices to engage with refugees and asylum-seekers as a way of supporting their mental health. Within it there was lots of learning, new findings that we found fascinating, one of which is the importance of creating spaces that are beyond language. lots of people who are new to this **context** would struggle with language anyhow, But even if that is not the case, there are lots of activities, dance, visual arts and other activities, they can open up different ways for people to process what's happening. We found it even in our own experience a very empowering and interesting space to explore.

Connectedness

Another thing we've discovered is the importance of connectedness. That also refers to your earlier question, Cornelius, of how you support artists and practitioners and our team members who are engaging in these activities. We find that providing spaces of connection, developing networks where people can share their experiences, where they can share good practice, is hugely important. That's one of the things that we are doing at the moment, developing these networks - almost an ecosystem of organizations and practitioners who wanted to work in this space - so that we can do more sharing, we can develop language, maybe be more of a common language so that we can better understand each other when we talk about these things and share training, share good practice and so on, so that element of connectedness is as important I feel to the practitioners and artists who work with refugees and asylum seekers, as is important for asylum seekers and refugees because that sense of belonging and creating a community of people who are there with you, even if it's for periods of time, can be read, can be making huge difference in their lives.

Christopher Bailey, WHO And I would just add to that that. There's something unique about the arts and especially and including the non-verbal arts in creating and supporting that sense of community that when you sing together in a choral group, when you play together in an instrument ensemble, when you dance together, there is an oxytocin reaction in the brain - the hormone that does reward and support bonding between people quite literally at a biochemical and neurological level. It's not a soft science anymore. We're actually understanding not only the hard science behind it, but how this may have evolved in the history of our species.

We're the only species on this planet that practises music and moves to a beat. The only other species that can move to the beat is a parrot and only when they've been domesticated and have been exposed to human behaviour. So it's something quite uniquely human to us. And there's a reason why it evolved**.** Everything has a reason and part of it I think is because of this sense of community that gave us a better chance of survival and allowed us to thrive even in situations where we have been forcibly to place displaced for whatever reason.

Professor Katona Thank you both for a really stimulating discussion. And thanks very much to Veronica for organising this session and also for organising the meeting as a whole All the very best you both.

Alexandra Coulter, chair Thank you. Cornelius is now here with us. Thank you. That was absolutely fascinating. What a brilliant start to this event from people who have such deep experience and knowledge and some very interesting themes coming out there, which I'm sure will come out in the panels during the rest of the event, especially around language and non-verbal communication, and providing those tools for self-care but also to support people to sustain their wellbeing. whether they're forcibly displaced people or the people who support them, and this interesting discussion around connection. So, thank you very much, Cornelius and to Christopher and Almir.

I will hand over to Cornelius now to chair the next panel.

Professor Cornelius Katona, chair Thank you so much, Alex. It's a real delight to be here not quite in the flesh, but at least in real time. Now I've got the pleasure today of introducing what I think is quite a fascinating panel of practitioners in the field. I think the intention is that the themes that connect these different presentations will emerge as the session progresses. It's a great pleasure to introduce Daniela Nofal.

DANIELA NOFAL, Producer at Counterpoint Arts. Her particular focus is on producing, commissioning and programming artistic projects at the intersection of displacement and mental health. Daniela has been working as a cultural organiser and arts practitioner, and has produced various artistic projects and creative interventions, sitting at the intersection of art, arts education and social engagement. Over the years, she has collaborated and worked with a number of organisations across the UK and internationally, including Beyond the Now, Shubbak Festival and Ettijahat. I should also say that she is here as a representative from Counterpoints Arts, which is a leading national organization in the field of arts, migration and cultural change that supports and arts, bind about migrants and refugees seeking to ensure that their contributions to recognize and are welcomed within British art, history and culture. Mission is a belief that the arts can inspire social change and can enhance inclusion and cultural integration. Their work takes place at the intersection of climate, racial justice, mental health and displacement.

Daniela Nofal, Counterpoint Arts

Good afternoon. Thank you so much, Cornelius, for the introduction. It's such a big pleasure to be here with you all today alongside so many incredible speakers.

Psychosocial experience of forced displacement

I will begin by offering some context of the psychosocial experience of forced displacement, which I hope will offer a backdrop to a lot of the work that we do at Counterpoints Arts, but also for many of the projects that we will get to hear from during this afternoon's session. But also importantly I'd like to situate the traumatic experience of displacement within wider systems and structures within wider systems and structures that shape the contemporary world.

The Psychological impact

The psychological impact of displacement is an urgent matter and one that many of us are reckoning with today, making it a major public health concern. The UNHCR estimates that in 2023 over 110 million individuals worldwide were forcibly displaced. Whether that is due to war, human rights abuses, fear of persecution, or climate catastrophe. In fear for their lives, people find themselves forced to leave their homes, their communities, their countries to find safety and sanctuary elsewhere. This uprooting and extreme sense of loss can, in itself, be an overwhelming and traumatic experience. But it does not end there. Many end up having to embark on life-threatening journeys to find safety. As a consequence of racialized violent border regimes that seek to keep migrants out, innocent people seeking refuge are forced into taking dangerous routes, from taking treacherous sea crossings to travelling with smugglers. These experiences expose people to immense distress and danger.

For those who eventually arrive at shores of safety, they find themselves welcomed by hostile governments and policies that go to extremely far lengths to make their lives unbearable, to deem them as illegal, criminal even. Stripped of their humanity, many find themselves ending up incarcerated in detention centres whose conditions mirror those of the prison systems.

Speaking to the experience in the UK, the UK is the only country in Europe where people can be detained indefinitely. Also the introduction of the hostile environment policies in 2012 makes sure that undocumented migrants are unable to build a life, unable to work, unable to access healthcare - these basic necessities to live a decent life. These policies ensure that borders are not only felt at the edges of the nation states that creep into society into the very hearts of our public services, as doctors, teachers and landlords are expected to act as border guards asking for proof of migration states.

So what this framing helps elicit is the compounded effects on the mental health and wellbeing of sanctuary seekers from being forcefully displaced. So even when arriving into a new country where they have to navigate violence systems that strip them of their dignity on a day-to-day basis.

Refugee Council findings

As a result, but also as a consequence in research by Refugee Council, they said that 61% of refugees and asylum seekers experience serious mental distress.

Healing power of art

For us at Counterpoints Arts, we believe in the power that art can play to open up spaces of sanctuary where we can begin to heal the pain, to move beyond trauma narratives that risk deeming individuals as inherently broken, where people can reclaim the parts of themselves that had to be locked off in order to survive, where narratives and stories can be reshaped and told with agency - whether that be through comedy, through film, music, dance, theatre. Over the years, as an organization we've had the immense privilege of collaborating and partnering with a whole range of artists, organizations and institutions that do incredibly ground-breaking work out there, who work at this intersection of displacement, mental health, and the arts, that bring art to newly arrived sanctuary seekers and migrants wherever they be.

Counterpoints Arts projects

Just to give you a flavour of some of these projects and initiatives out there: some go into the heart of detention centres, others go into the contingent accommodation available such as hotels and hostels where many find themselves living. Other projects go into community settings - so from the street level to the neighbourhood level. Other projects are run within organizations that, for example, either run one-off projects for refugees or are community arts organizations that specialize in working with refugees or led by refugees and of the experience of displacement. The nature of these projects varies tremendously from one-off projects running for a couple of hours to longer term projects that run for months or even years.

All in all, these projects speak to the power that art can play and then the transformative capacity of art to touch the lives of sanctuary-seekers. At Counterpoints arts, we find ourselves working in this incredibly diverse and rich ecosystem.

New network of creative practice for refugees

Over the next two years and as part of a new strand of work that we're developing, focusing on mental health, which Almir spoke to earlier, we are working on building and nurturing a new network of creative practice to foster connections across the sector to bring more collaboration to life, to learn from each other about what good practice looks like, with the overarching aim of supporting asylum seekers and refugees across the country and beyond. There's so much that we can learn from these initiatives, learnings that can go far beyond the migration sector.

I'm really looking forward to rest of the talks this afternoon which are going to give us a flavour of the incredible, inspiring work that they do. Thank you so much.

CHAT **Daniela Nofal | Counterpoints Arts** : Here is a link to the report Counterpoints Arts was commissioned by The Baring Foundation to put together on Arts, Mental Health and Refugees - https://baringfoundation.org.uk/resource/creatively-minded-and-refugees/
You can find out more about our new strand of work on mental health here, feel free to get in touch with us !https://counterpoints.org.uk/our-new-programme-on-art-displacement-mental-health/
Berni Godinho: Thank you ! Wonderful !

Professor Katona Thank you so much.

The next presentation is from

BOBBY LLOYD, who is a visual artist, art therapist, supervisor, lecturer and the CEO of Art Refuge. Bobby has worked for many years in the NHS and in community settings, as well as internationally, in context of conflict and social upheaval. So, programme delivery on either side of the Channel. In the past nine years she's become increasingly interested in the roles of socially engaged art and art therapy in relation to displacement, to crisis support, to co-production and to community and social justice.

Art Refuge is a UK charity that is quite long-standing. It was founded in 2006 and uses art and art therapy to support mental health and wellbeing of people displaced due to conflict, persecution and poverty both in the UK and internationally. Art Refuge delivers long-term programmes and takes part in short-term projects, public exhibitions, conferences, cross disciplinary collaborations and in research, as well as delivering tailor-made trainings and skill-sharing activities to frontline workers, most recently in Western Ukraine. Working in close partnership with other organizations, Art Refuge's longitudinal psychosocial group programmes take place for refugees and asylum seekers are located on both sides of the English Channel. So in northern

France and in southern England, in day centres, in drop-in spaces, in refugee camps and in hotels. The trauma-informed work is led by an experienced freelance team of registered art therapists and artists, including artists with lived experience of displacement. Bobby, over to you.

Bobby Lloyd, Art Refuge,

Thank you so much. [shows slide from the Art Refuge table:

It's summer, 2017. A day centre on the edge of Calais, northern France. Two young men from Afghanistan have been sleeping outside for several days trying to reach the UK by truck across the English Channel. They join the Art Refuge table, where we have provided a tablecloth map, miniature bricks and a small yellow truck. The young men play together. Their breathing regulates and they are absorbed for a period of time. Participants speak in different languages, moving the loaded truck, creating aa building:

I just wanted to share that little clip to give you a sense of what we do.

Community Table,

I am going to introduce now the model that we've been developing over the last few years – out of the Calais context – and also work in a safe house. We have developed a model called the Community Table. It's an open access psychosocial model to support the mental health and wellbeing of people displaced. Those are people displaced on borders, people on the move and people in the asylum system. It's joined largely by men from across North and East Africa – that is Eritrea, Ethiopia, Sudan, South Sudan and the Middle East, Syria, Iran, Iraq, Kurdistan, Afghanistan, Yemen, and also further afield.

Collaboration

Always working in collaboration with other organizations, we go to where people are located; and as Cornelius has already said, we work on borders, we work in day centres, we work in both makeshift camps and also the Home Office run large camps in the UK now and in hostels. Currently we're working in Paris, Dunkirk, where we were yesterday, Calais Kent, Essex, London and Bristol.

What's unique about the Community Table is that those who are displaced, alongside the community around them - so that might be volunteers, interpreters, NGO staff, even sometimes security guards - are welcome to join, offering temporary community for even the briefest period of time for everybody at the table.

Against the ever-harsher hostile policies and uncertainties that are part of daily life, the work aims to support the resilience of people. Their capacity for imagination, hoping and coping, communication, meaning making and solidarity – and indeed, and this is also special to the

Community Table – to support the mental health and wellbeing of all those taking part in a context in which burnout is so prevalent amongst frontline workers.

Adaptability

Being a mobile project, we adapt our work to context - that's to the weather, to the setting, the political context and of course to the people present. We think carefully about intentionality, which includes the materials and the tools that we introduce. Often pre-used, we have for example offered manual typewriters at the table over a number of years. If anybody is interested from a neuroscience perspective,* we'd be very interested to hear from you. We've been really thinking about what it is that these typewriters offer, because we've seen how valuable they are in supporting a positive physiological response.

I exist. My name is. I have value.

Abdullah typed letters to all those who had helped him along his route, taking the letters with him to his tent on the edge of Calais, rereading them when needed, reaffirming his sense of himself in relation to others, returning to the Community Table in a day centre in Calais over a number of years because he was stuck in France, he spoke of the Table like this:

It's like when you go to your grandmother's house with an atmosphere like that. All people young and old. When I need time for myself, I go there.

Just to end that many people we see only once. So, we extend our work into the space of social media for ongoing connection in the virtual space. But sometimes we meet people at the Community Table again in the UK. It might be in a hotel. It might be one of the camps. It's familiar and it's familial. And for volunteers and others who join our tables, we also offer skill-sharing and training in addition to community and wellbeing support. Thank you so much.

***CHAT Veronica, host**: Our next refugee webinar will include the neuroscience perspective

CK, chair Thank you so much. That was that was brilliant. Now, I'm delighted to introduce Sheila Hayman

SHEILA HAYMAN is the Coordinator of Write to Life, which is the therapeutic Creative Writing Group of Freedom from Torture. She's been doing this particular line of work for over twenty years and is justifiably very proud of it. Says this is the longest running therapeutic running group in the UK, as well as the only one specifically for survivors of torture. As a child refugee from Nazi Germany herself, with a parent who became a distinguished mathematician, she was used from an early age to visitors from around the world and relishes the mix of cultures that her current work involves. In her other life, she's a documentary filmmaker, a writer and a journalist whose films have won a BAFTA Timeout Documentary Series of the Year, Arts Documentary of the Year nomination, and the Robert Kennedy Award. She's been UK Young Journalist of the Year, the BAFTA Fulbright Fellow in Los

Angeles. She was also Artist in Residence at PIK Potsdam Working on the carbon footprint of AI. And she's on the board of the Minderoo Centre for Technology and Democracy in Cambridge.

I should also say a few words about **Freedom from Torture**, which provides specialist psychological therapy for asylum seekers and refugees who survive torture, helping them to recover, to rebuild their lives in the UK. Freedom from Torture also provides a range of other therapies including gardening, bread making, music therapy as well as **Write to Life**.

Sheila Hayman, Freedom from Torture, 'Write to Life',

Since you started talking about AI and intelligence just off the back of what Christopher was saying and what Bobby was saying, one of my interests is in embodied intelligence and I can say that when people dance together or play music together or sing together, it's not just a matter of getting oxytocin, they actually synchronize their brain waves and heartbeat, so you do actually become a single organism when you're doing something like that together. That's really worth knowing and all on the back of what Bobby was saying, yes the neuroscience is very clear that when you type something physically you know on an analogue machine it has an effect on your brain completely different from just touching a screen. All hail the analogue, long may it continue!

Agency, autonomy, work, freedom

The other thing I want to say before I start talking about Write to Life is - and I hope people will forgive me because I'm a huge fan of everybody who's spoken just now and lucky to be friends with them - I do think that actually above anything that we can offer, the most important thing to make people happy and stop them from being mad, is agency autonomy work money and freedom. Until we give our refugees and asylum seekers those things everything else that we do – although it's fantastic and will enhance their lives in many ways – is not going to ultimately lead to long-term happiness. That's what I believe anyway. I also wanted to pick up from what Almir was saying that the non-verbal is really important to us at Freedom from Torture.

Gardening and horticultural therapy – Chelsea Flower Show Freedom from Torture garden

So we ave a gardening group, horticultural therapy group which can work largely without words. We've just been lucky enough to have a garden at the Chelsea Flower Show this year which is celebration of that work.

Bread-baking

We have a bread baking group because as we all know one of the overarching principles of asylum in this country is that if you can cook, you are more welcome than if you can't. So people bake bread of all kinds from all over the world as part of our therapeutic activities. They knead it and shape it and watch it rise and come to life together – that's a big part of what Freedom from Torture does too.

Write to Life

As for Write to Life, it has been running nearly 25 years continuously and some of the members have been here almost in the beginning, which is a hugely important thing because if you have been tortured and you've come to a country where you don't know anybody, counterintuitively, the people from your own culture may actually be the people you can least trust, least rely on. People are often even more isolated than they might be otherwise. So when they come to a group where people may be from completely different countries, but have had the same emotional and psychological experience, they discover that they can trust each other because they don't need to explain things. Our group becomes a second family and people travel for extraordinary long distances to just sit around a table and eat an indifferent meal and just be together and write.

Creative purpose – self-expression, rebuilding new identity, reaffirming your voice

Its purposes are creative, obviously, self-expression, rebuilding a new identity. One of the objectives of torture is essentially to destroy your identity and make you feel that you don't exist and that you are worth nothing even if you did exist. When you write something on a page and there it is in front of you and it comes from a voice that you may not have even known was inside you but clearly is, it actually reaffirms the fact that you do exist; and when you read it out to other people and they listen, people have said to me that it's like holding a mirror up and actually seeing that once again you are a person, you do have a voice, you do have an image, you do have something to say and you are valued. So that's a really important part of it.

Writing as therapy, regaining control

The therapeutic aspect is also really important. People often come to us, tormented by appalling nightmares of the stuff that's happened to them. If it's not processed, it just goes round and round in their heads. They are terrified going to sleep for fear of what they might dream of. If they're not sleeping they can go mad with insomnia. So we have to try and find a way of taking those nightmares out of their heads and onto the page and having put them on the page, they can then control that narrative. It's theirs to control and shape, rather than having control of them. So we encourage people even when they go to bed to have a pen and paper by the bed to write down anything that comes to them in the night so that it's not running them and they're running it.

Referred to Write to Life by Freedom from Torture clinicians

Having told these stories - we don't on the whole encourage people to write about their bad experiences because we're not therapeutically trained, we're not psychotherapists – people come to the group referred by their clinician at Freedom from Torture, they all have clinicians, but they're allowed to stay as long as they like. Often they stay long after their clinical treatment has ended and we become a kind of bridge from Freedom from Torture treatment has ended and we become a kind of bridge from Freedom from Torture, the therapeutic side of Freedom and Torture into the new world.

Pain powers writing

They come to us having been recommended by their clinicians and they don't necessarily write about their experiences. They are free to write about whatever they want to. But the pain that they have had is often a kind of rocket fuel for what they write – many of them do choose to write about that stuff. The rocket fuel is what they've gone through. It's the power, gives the power to their words and their stories. We then help them to sheathe it, as it were, in the stealth weapon of art.

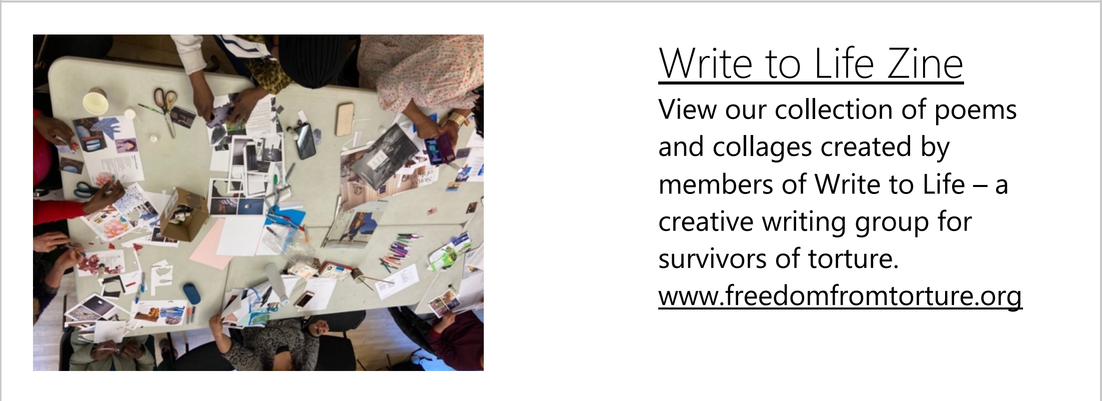
Beauty

So beautiful words or beautiful images in the shape of films or beautiful sounds if we turn it into music, can enable those messages to penetrate the defences of the hostile or the indifference of those who don't really care and haven't really thought about it one way or another. So I think by making art, and I'm sure this is the experience of lots of other people who are on this panel today, by making art out of the experience of refuge or torture or any of these other awful things, we are able to get it to places that would never ever be able to be reached by yet another diatribe about the awfulness of the system or yet another complaint about the misery of people's lives. That's really important to us. That beauty really touches the people who make it, as well as the people who experience it, I think,

The Writing Group

So we start with writing. We have a writing group which meets as a group every two weeks and everybody in the group also gets one-to-one work with a writing mentor. In addition to that, we have these special projects to widen our impact and our reach. We've grown from a few people just writing for each other, to a group writing for online and print. and performing through plays, mime, films, musical narratives and other things. We've collaborated with the V & A, the British Museum both Tate Galleries, the Roundhouse and Kings Place. We're always looking for new creative partners to work with

Zines We also send out our work in the form of Zines which are with handmade, literal physical copies of zines which we get together with scissors and paper and put together which is enormous fun, about twice a year.



Write to Life Zine

View our collection of poems and collages created by members of Write to Life – a creative writing group for survivors of torture.

www.freedomfromtorture.org

Professor Katona Thank you, That was s lovely presentation as indeed all three were.

PANEL DISCUSSION, chaired by Professor Cornelius Katona.:

Professor Katona One theme that seems to come through from all three of your presentations is the notion of people who are not psychotherapists doing this work. Another thing that came through was about the potential for stress and burnout. I am just wondering whether you might all three just say a little bit about what is the best way to approach training on the one hand and support and avoidance of burnout on the other, among the staff and the volunteers who work within your projects.

Sheila, Freedom from Torture In our project we do in theory have the support of the clinicians who work with our clients, but they don't all have clinicians obviously because sometimes they finish their clinical treatment before we've stopped working with them. I guess actually for a lot of the people who work with me, writing is in itself to some extent a way to process, you know. We process our experiences in the same way as the people in the group do. But often, as I said, we give them the choice really. It is not like the therapy that they receive where often they don't feel in control and they can be ambushed by a flashback or some dreadful episode when they're not expecting it and don't need it. They feel much more in control of the progress of their journey, I think, by doing it through writing, which they can do when they choose to and how they choose to.

So I don't think we're exposed to a lot of grief. But I don't think necessarily that we're exposed to quite as much trauma as some people who are working really on the front line without the support of clinicians.

Bobby Lloyd Art Refuge is made up of a team of freelance therapists. We're all art therapists. Also we work with artists who have lived experience of displacement and we bring other people in. But being therapists ourselves enables us I think to deal with the uncertainty to go into all sorts, a range of different contexts and to be able to be present in those contexts with whatever comes.

For example, going into some of these larger camps which are intimidating spaces and being able to sit with people with whatever they bring. Often in those settings where we're working with people in limbo, it's really about just being able to tolerate, listening and witnessing. But it also could be a little bit more. We bring in artists who are refugees themselves, with refugee backgrounds or other experiences of displacement because we haven't got that knowledge. We try and mix it up. I think the work does enable us to see the bigger picture, to zoom in and out. With the sort of thinking brain. We do a huge amount of reflecting and thinking after and before and around the sessions. This all enables us to be present with people.

Professor Katona Thank you. Daniela?

Daniela At Counterpoints Arts, we have a different lived experiences within the team. Also the artists that we work with have different lived experiences. Recently since launching this new strand of work around mental health, we've been having various conversations as well around artists stewarding the work of others, particularly artists that are working socially engaged capacities and rethinking what kind of support are needed to be offered to artists who are leading on this work. I think that requires organizations generally to rethink processes and structures, thinking about supervision, thinking about any additional resources that need to be built into the design of projects, how much time is given, how much resources in general. That's a conversation that's been very much alive for us. It's always very present in the work, but we're in conversation with artists around what we can do to support them when leading on this work. But also internally we've been doing training on trauma-informed practice with a brilliant organization, Kazzum Arts, but also Amna International as well.

There are brilliant resources out there that can help organizations and individuals to reflect on trauma, how it appears and how it manifests and how most of us have our own trauma and how that can be activated and how we can embed that awareness in the different processes that we work through and work with.

Professor Katona Thank you. One other thing that struck me listening to the three presentations is that there was a lot of commonality. I think it's one of the underlying assumptions behind today's conference that there are commonalities across the arts. There are ways in which art in a general sense is a good thing in the refugee asylum and mental health trauma context. But I wonder whether any of you might want to say anything about comparing and contrasting about horses for courses, the difference between working in a written medium in a dramatic medium, in a visual medium.

Bobby Lloyd, Art Refuge I think at the Community Table – it's only one of the models we use, but it is our core model – we use visual art. It's our main art form. All of us art therapists, and of course those people joining us around the Table all make our visual art together. That is a really core element of the work. Sometimes we need to bring in other art forms. So that's where the difference lies = we really have this absolute urge to bring in dance movement and we find and source and collaborate with others across art forms. So I think in that sense we're strong in what we are and who we are. That's how we work. Sometimes the other art forms are absolutely critical in enabling us to offer something that's bigger and richer and adds to the joy.

Sheila, Write to Life It so happens that we work primarily with writing, partly because, as I said, the urgency of enabling people to speak for themselves and to have a voice is really important to us. But as I was trying to explain with the other forms of therapy that that we have at Freedom from Torture, there are other forms that are non-verbal and that work through and that is I think absolutely crucial for people who maybe don't have so much language or just express themselves in different ways.

Professor Katona Thank you.

Daniela Counterpoints Arts I’m also happy to reflect. At the minute there's two projects that came to mind as you were asking the question.

Comedy

One is No Direction Home, which Almir spoke about, which is around running comedy workshops with asylum seekers and refugees. And that, for example, is really around reclaiming a narrative, reclaiming a story, remembering. There's a lot of laughter and joy and I think that playfulness really unlocks a different sense of presence in the space. It is a reminder of the parts of ourselves that might have been locked away because of the traumatic experience one has been through the violence systems when they're in, so it's about regaining access to those parts that never really left us. They're always parts of us.

Then for example another project which we're running with a commission with Kadir Karababa who is an artist, running singing workshops and thinking about singing and voice and that somatic capacity to unlock certain things in the body. There's that release that comes with it and I feel each art form does offer different ways of accessing certain parts of the body or certain parts of the self. There's a whole array of art forms, but each of them, I think, leads to different ways of reclaiming one's agency, one's voice, accessing parts of oneself, and also being able to do that work within the body, in an embodied way, so that there's that muscle memory that takes shape and takes hold of these positive and joyful experiences.

Sheila, Freedom from Torture Can I just say one last thing about comedy? I think that's absolutely true. But I think the other thing is really important about comedy is it's about power. If you make fun of something, whether it's the asylum system, or other things that people have done to you or people's cruelty or people's composite, you become in control of it. You control the narrative and that gives you power over them, which is why all dictators loathe being made fun of. So I think one of the really important things about doing comedy with people who've endured this kind of experience is that it gives them the power to control the narrative of what's happened to them.

Daniela, Counterpoints Art Exactly, exactly. And you can do things the language you know you can speak about the systems that that have excluded you, so you can exclude them in a way through having that sense of control again. think these all speak to the power of art in its different shapes and capacities.

Professor Katona Can I thank you all three very much for wonderful presentations, wonderful discussion.

Togetherness, relearnng trust

Just one tiny observation from me to try and bring it to a close. One of the things that struck me most hearing you all is about togetherness about the notion that you are all working with people together. There's this notion of the collective functioning and I think that one of the elements of that has to be about relearning trust, relearning to work together, which is I think one of the key things that's been implied in a lot of what you say and certainly resonates very much for me. So thank you all three very much indeed for wonderful presentations and discussion. Thank you.

Veronica, host Thank you, Cornelius, very much for your wise chairing, and thank you Daniela, Bobby and Sheila for discussing your phenomenal heart-warming work.

Now we have a musical interlude:

The Unknowns

Hear Me Out refugee band, performing

<u>Hope to humanity</u> . . .§2z’

Love is the greatest . . .
Never forget that you
humanity come before race
Never forget

Performed by Kwaku (vocalist and keyboard player from Ghana), Kidu (drummer from Ethiopia, Aksa (vocalist and lyricist from Kosovo), Esmaeli (percussionist from Iran), Ehsan (Cajon player and rapper from Iran) and Ardavan (guitarist, vocalist and lyricist from Iran), Anna (drummer, Hear Me Out Artist).

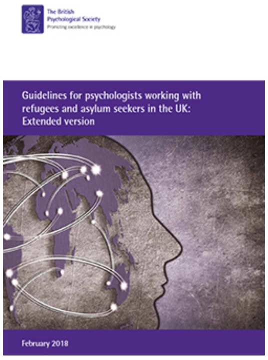
CHAT Berni Godinho: Great work for Humanity!

Veronica, host Warm thanks to the amazing Unknowns!

I should like to introduce Professor Rachel Tribe to chair our next PANEL. You are warmly welcome, Rachel.

<u>PROFESSOR RACHEL TRIBE</u> is Professor of Applied Psychology at the University of East London and Queen Mary, University of London and chair of the international mental health charity <u>Careif</u>. She has worked clinically and published widely on migration and mental health, refugees and asylum seekers, and trauma; and is team leader for the <u>Refugee Mental health and Wellbeing</u> resource portal.

Professor Tribe is a member of the human rights committee of the British Psychological Society, whose guidelines on *<u>Working with refugees and asylum seekers</u>* and on *Working with Interpreters in Health Settings* she has co-edited. Her book on *Working with Interpreters in Mental Health* is currently being updated. Professor Tribe is a member of the <u>World Psychiatric Association's</u> Task Force on Migration and Mental Health.


The British Psychological Society
Promoting excellence in psychology

Guidelines for psychologists working with refugees and asylum seekers in the UK: Extended version

February 2018

Professor Rachel Tribe, chair

Well, thank you very much. It's a privilege and an honour to be here. These are amazing speakers. I also want you to thank Veronica for all the hard work she's gone to in organizing today.

Refugee and Mental Health and Wellbeing Portal

I am going to briefly mention resources, one of which is the Refugee and Mental Health and Wellbeing Portal I set up with the team of refugees, community groups, and other people. it has a whole range of resources, but we're always interested in adding to it. We do a big update once a year. We do it in our own time. So if anyone has any resources they would like to add to that, we would love to hear from you.

Now, I'm going to introduce our first speaker on our amazing panel this afternoon, Sara Green, who is founder and Executive Director of A.R.T. for Refugees in Transition. Welcome, Sara. We look forward to hearing you.

SARA GREEN, Founder and Executive Director, A.R.T. for Refugees in Transition, New York

Since 2003 Sara has implemented programmes for refugees, displaced migrants and marginalized communities, with programmes in Thailand. Columbia, Egypt. Jordan, Israel. Cameroon, Tajikistan and Palestine. Accredited by UNESCO, A.R.T. was awarded the Jeonju Award 2023 for Presentation of Intangible Cultural Heritage.

Sara Green, A.R.T. for Refugees in Transition

Thank you very much for having me. The work at my organization does is very important and much needed as we mark today, World Refugee Day. I want to thank Veronica for hosting this panel and bringing voice to the need for the arts, refugees and for the recognition that these people deserve dignity.

The work that we do focuses on having the elders in the community teach the youngest generation their cultural heritage, therefore creating community and identity. It's a very important bond. A very much an important part of our identity is our culture.

I want to take a minute to speak about a project we did late last year. We all know the events that are happening in the Middle East right now. We had a programme running for three years in the West Bank, in a Palestinian refugee camp. When the events of October 7th unfolded, obviously the world changed. My country director asked me ‘What can I do? Everybody is home. Everyone is traumatized. And everybody is scared.’

Elders singing lullabies to children in Palestinian refugee camp to preserve their heritage

We had worked during the pandemic in this camp where we had programmes for the grandparents teaching the children their crafts and their stories. So we started a programme.

where we had the women in the homes sing lullabies to the children. What we found was that it created a sense of peace and a sense of trust within the family and the elders there, the fathers, the children, the mothers. As a result, the mothers in the camp formed a WhatsApp group to discuss this. Then we started a nightly WhatsApp Lullaby Hour where they could tune in and either sing or listen to lullabies. We forget that our culture has not only an effect on building our identity, but also in helping us in times of need and in trauma.

If we can call from the identity of the heritage that it will help by preserving and perpetuating and also documenting the cultural heritage of these refugees. We are helping them remember and to live with this heritage which serves as a means to deal with the trauma that they are dealing with and focusing on because of their displacement.

Professor Rachel Tribe Thank you for, a really moving and important talk.

Dr Hanan Khalil is an associate professor of neurological rehabilitation at Qatar University at Doha in Qatar and she's very welcome. Over to you.

DR HANAN KHALIL, Associate Professor of Neurological Rehabilitation at Qatar University, Doha.

Thank you so much. Rachel and thank you so much for Veronica and organizers for inviting me to speak to you today. It's a true pleasure to be with you. My name is Hanan Khalil. I'm originally from Jordan. I've done my training in physical therapy in Jordan and then I went to the UK, to do my Masters and PhD in Cardiff University in 2016 very much focused on brain health and how movement could help particularly in the area of dementia. But, as you know, there is ongoing conflict in the region and Jordan has witnessed an increased number of refugees, particularly at the time of the Syrian war. In fact, according to the UN stats, Jordan is ranked as the second country in the world and the number of refugees per 1,000 people and most of them are from Syria.

As the previous speakers have indicated and mentioned, a lot of those have experienced torture and a lot of them have also experienced trauma. We have stats and some publications which indicate that emotional and mental health problems are very prevalent among Syrian refugees, particularly when it comes to stress and anxiety, depression and also post-traumatic stress disorder, which can lead to chronic pain, sleep difficulties and then decrease in function. But at the same time with all the mental health problems there is very limited access when it comes to the mental health services.

The intervention of the toolkit that I'm using, this is slightly different than the others in terms of the arts. We use a lot of movements. I'm a physiotherapist by background, and we like movement and movement-based exercise intervention.

When it comes to the work with the refugees, there are a lot of NGOs and organizations trying to help refugees in Jordan. However, among those organizations who are focused toward delivering let's say something specific to mental health is very limited. A lot of them focus on the physical endurance.

Collaborationii with Centre for Victims of Turture

There is one to my knowledge, one in Jordan, that does incorporate movement-based therapies, which is called a Centre for Victims of Torture (CVT). We've been collaborating with the CVT as an academic institution. I've been working for years in the Jordan University of Science and Technology toward building trauma-focused physiotherapy services to the Syrian refugees or to the traumatized refugees in general.

Neuroscientific impact of physical exercise

But I do believe that there is a strong rationale for using exercise and movement-based interventions. Because when it comes to the exercise science, we know that exercise can increase the flow, can reduce the sympathetic nervous system activity and can reduce the cortisol level implicating the hypothermic pituitary adrenal axis and can improve the release of numerous neurotransmitters, that it does modulate stress, pain, sleep and mood as well.

Multidisciplinary trauma-focussed movement-based group intervention

So the safety intervention is really a group-based intervention. It's a ten-week cycle. It's manualized. The aim for treatment is really trauma-focused, using the movement within a multidisciplinary approach. Each client would also have received counselling from a psychologist and also counselling from a social worker. The guiding principle for the movement-based intervention is really trauma informed biopsychological, biopsychosocial and also being tailored to the individuals.

Academic and educational evidence-informed trauma-focussed physiotherapy

So our journey with CVT is a cross-cultural collaborative approach with continued emphasis on a trauma, both from an academic perspective, but also from an educational perspective, to progress towards evidence-informed, trauma-focused physiotherapy interventions.

Findings - Intertwined physical, social, psychological trauma-informed approach is key throughout care pathway

We've done a lot of cross-sectional qualitative work in terms of focus groups with therapists working with these clients and also with the clients themselves. There are many lessons that we have learned. One of the very most important, which as maybe everyone does know that intertwined physical social, psychological symptoms are a key feature of clinical presentations for trauma exposed refugees that the client-centred approach that incorporated trauma-informed care and the trauma-focused care is really important. It's really critical throughout the care pathway. We knew that services usually or often are not prepared to deliver that kind of intervention and that training gaps are evident. We've worked with the CVT toward finding ways to increase access.

Digital resource

One of them is adapting their intervention for remote deliveries. so we created a lot of resources that would support the remote delivery for their intervention. In the UK we collaborated with Cardiff University for peer delivery of the intervention. Currently we are working on building resources to raise awareness in refuges and also educational programmes for capacity-building among universities and also among healthcare professionals.

Thank you so much.

GBHI PT Resources (YouTube): CVT Physiotherapy Services Awareness; Progressive Muscle Relaxation; Posture and Ergonomics; Body Scan; Breathing; Mindful Movement

Professor Rachel Tribe Thank you, Hannan. That was a really interesting talk. It's interesting how the complementarity between different speakers doing different things, but all coming with the same ethos and commitment to the work. So you are very welcome and thank you.

It's now my pleasure to introduce Lis Murphy, who is Creative Director and Founder of Music Action International.

LIS MURPHY, Creative Director and Founder of Music Action International (MAI),

Lis Murphy has pioneered the use of singing and songwriting, co-creating programmes with war and torture survivors. She has facilitated skill-sharing and programme delivery with local people in Bosnia-Hercegovina, Georgia in the Caucasus, Palestine, Ireland and Sierra Leone.

Thank you so much. It's been really fascinating today to hear from lots of different speakers from different art forms, different approaches, but I think there's huge commonalities with the work that we do as well.

Just a bit about the background of the founding of the organization. I'm a musician and my first job was working in Bosnia Herzgovina in a couple of years after the war there. I lived up there for two years and worked with a local team with facilitating music problems with children. I learned a huge amount while I was there and I really wanted to take the ethos and the inspiration of a lot of the young people that I'd worked with and to support refugees and safety-seekers back here and also people who were displaced in different communities.

One of the main things that influenced the methodology in the beginning was within Bosnia, the setups of some of the NGOs meant that the local people felt they weren't always listened to or they didn't have influence in the programmes and now ‘lived experience’ is a very common term. It is really amazing to see how that shifted. I think for us that was really key in the beginning that people with lived experience were at all levels of the organization and in the facilitation team.

The methodology of everything we do is very similar. It's around creating a safe space and sharing songs and language from different countries and then creativity, creative writing, usually towards some sort of performance or video. The way that we structure it is that we have trained facilitators who are trained in trauma awareness, refugee awareness who are, I think, a majority global majority and with lived experience. They are professional musicians or dancers, or poets. They then work with people who are in the absolute crisis point to use music, particularly music, but other art forms as well as way of reducing the trauma and stress that we've been talking about, that people have back home in their country, but then also with the systems that they're facing here.

Another strand that I want to pick up on was that we were really lucky with our first programme that we did with torture survivors was in partnership with Freedom from Torture in the north-west.

Health and Wellbeing of Staff

I talked to them about some of the impact that Bosnia had had on me and they basically diagnosed me with vicarious trauma. Because of that, this health and wellbeing of the staff and the people that are working directly with participants has been an intrinsic part, developed with the clinical psychologist but also with refugees and people from different backgrounds to make sure that we don't call it supervision - because we found out musicians don't turn up if you call it that, we call it wellbeing support - but that it's structured in all the programmes and in the way that we bring groups together.

In the past we've done skill sharing in various different places – Palestine, Georgia – and we've got an ongoing project in Sierra Leone, but the majority of the work we do at the moment is in the UK. That's with all age groups. A with teenagers with torture survivors, in primary schools as well. One of those programs is called Crisis Choirs. So I shall hand over to Ramsey who runs Crisis Choirs.

RAMSEY JANINI, Creative Producer, Music Action International's Crisis Choirs . Ramsey is from a family who were ethnically crowd cleansed from Palestine in 1948. The Crisis Choirs led by refugee musicians for new arrivals at drop-in centres.

Hello everyone. Thank you for the introduction. Thank you everyone for the informative and inspiring talks.

Crisis Choirs as Lis mentioned is a project of ours that I am the project manager for. The concept of the Crisis Choir is that it's a singing group that takes place within drop-in centres. Going back to the very first speaker who was talking about that, the people we work with obviously have very complex needs -

Partnerships at drop-in centres, other urgent needs

Where the arts come in is not necessarily number one. So we're always working in partnerships that are looking at more holistic issues, or more about personal security around housing and income. They have support there, but also often they're given a slot at the centres and their waiting rooms, where there might be other activities going on, but sometimes people there are a little bit tense perhaps about an upcoming meeting and we're often setting up in those spaces.

We have a team of about two or three, inclusive of experiences of displacement, war conflict or a refugee asylum system.

Non-verbal approach

We create a circle. At first we would often open the session as has also been mentioned with non-verbal activities. It could be just copying body movements, a lot of those informed by studies of trauma and body movements that can help release trauma and regulate breathing and regulate blood flow.

Multi-cultural repertoire

From there we are working from the participants' experiences and languages. So we have repertoire of music which has been written in different programmes. Depending on the makeup of the group – let's say, there's a group of Sudanese Arabic speakers for example – then we'll have a number of songs that have been written, or they might be songs that are very well known in particular regions. It's always music which is either suggested by the participants which we learn, or we jam on very quickly, or otherwise works that have been written in different projects. All those. It's a mix of engaging the people there in their own languages, but also about sharing languages. As we get through writing music together that tends to be multilingual, part of it, like what we saw with the Hear Me Out performance just there.

Three regions

We work in three different regions and every project takes on particularities depending on the on the needs of participants there and in some respects on the characteristics of the support organization.

Rainbow Haven

In the north-west at the moment is a partnership with a wonderful group called Rainbow Haven, where there's a free meal provided in between our music sessions. As I am based in the northwest I'm very involved in that. We just had a culminating session for this project phase.

Continuity – inspiring generations

We stay with groups over time. We don't just continue our engagement.

There are a couple of new babies that have been born in the time. We're reflecting on how we had been singing to those to those children in the room and then here they were now. So just as a marker of the time that has been passed. It's wonderful to bring smiles to people's faces.

Rainbows Across Borders

In London there is a very special project which is a partner called Rainbows Across Borders, which focus on refugees who also identifies LGBTQ+, people who are doubly marginalized in many respects. That again has an inclusive team. They just had a performance at Queen's House on Sunday for Refugee Week which I hear went really well.

Offering pathways to employment

One thing that's special about that and one thing we try to emphasize is, although our work is engaging people who don't have any musical experience at all necessarily, if there are people with musical experience we also offer pathways to employment. From that partnership there are two young facilitators who trained with us a bit and are now facilitating other projects entirely as well as facilitating that group. So that's really a great story, that's our partnership with Rainbows Across Borders. Then we're also looking to expand to different regions.

Brighton

We have a project in Brighton which is just developing and there are our facilitation team includes a Ukrainian refugee and a Russian facilitator. So we're obviously all about bringing the world together and looking past issues of politics and you know, in an appropriate and sensitive way.

I hope I gave some sense of our, our attitude and our work.

Professor Rachel Tribe Thank you very much. Yes, you certainly did, Ramsey. That was, a really inspiring talk, and so much to think about. I think I could sit here and listen to everyone for talking for much longer.

It's my great pleasure to introduce Johanne, who can see this lovely smile in front, is Artistic Director for Hear Me Out, bringing music making into UK immigration detention centres.

JOHANNE HUDSON-LETT, Artistic Director, has worked as a freelance artist for Hear Me Out for over seven years. For the last 25 years her career has centred around the arts and media. From theatre acting to international marketing, radio presenter for the BBC, UKCCA Carnival participation manager to Senior Producer working to enhance and expand the artistic lives of young people in Luton. Johanne has always been passionate about working with local and marginalised communities as this is the world she grew up in and feels that now is the time to give back. Johanne is also a trustee for the Philharmonia Orchestra, championing our drive to welcome more diverse audiences and players.

Johanne Hudson-Lett, Artistic Director, Hear Me Out

Thank you very much and it's just so wonderful to be here in a room with such amazing people and hearing about everybody and thank you Veronica. We randomly met and so it's 1 of those things where the universe knows what it's doing. So here I am.

I'm the Artistic Director for Hear Me Out, only since January though, but my relationship with Hear Me Out started many, many years ago, when I started as a music practitioner working in Yarl's Wood Detention Centre. At the time, when I was working in there - I worked for about four years, it was a female only detention centre. I'd go, I'd run choir sessions and also run keyboard, piano sessions.

I'm giving back because the world wasn't kind to me as a child, lots of racial abuse because I live in a very white area in Bedford. I also went to a private school – that didn't help. I faced a lot of difficulties and struggles and I just thought, gosh the world needs to be a happier place. this is ridiculous. So, always interested in art and, I think from a very young age, I thought how will my love for the arts, how can I make it do good?

Hear Me Out

It wasn't until I started working in Yarl's Wood, that I felt this is where I meant to be, this was my calling, and worked my way up the company, I guess, is what I could say, and now I working with Hear Me Out and the work that we do~~.~~ At the moment, we're in two hotels, working with young children. We are also at Napier Barracks – (see page 00) – which is down at Folkestone – that's men only - and we send our artists into the various settings. We make music. Everybody is welcome to come and join us and make music.

We always send out two practitioners into whatever setting they're going to, because it's so important, as I know from being an artist myself, to have that support. Because we're working in very challenging situations and places. It's also for our own mental health and wellbeing that you've got somebody there to support.

As you heard, we have, we have a couple of bands. Actually, we've got three bands, which was not intentional at all.

The Unknowns band formed in asylum hotels

The Unknowns, who you heard earlier, that was Kwaku singing 'Hope to Humanity'. The Unknowns are all refugees in asylum seekers that we met in hotels when we went to the hotels to run sessions. And then the band formed and now I think they're fourth or fifth gig. And the joy that I see when the band is playing in that,

Music as outlet in desperate situations

we know that some of the asylum seekers are in desperate situations and they need an outlet. Music for so many of the members is their outlet. It's their way of reminding themselves who they are, reminding themselves of the strength that they have.

Commonality, family sharing stories – Hope

When they're working with other people who are in or have been in the same situation as them, there's that communality, there's that family, there's that bringing Hope, there's that sharing of stories, we allow that space for all that to happen.

And for one of the band members said to me yesterday, they've just done two gigs – one was in Richmond and the other one was in Wandsworth – and I've got another gig on Saturday and we've got a Band at the Barracks. I don't know if anybody's going to Hastings, if you're going to Hastings for the Sanctuary Festival we're going to be there with Band from the Barracks.

One of the members from The Unknowns had said, you know, Jo, playing with this band and having access to music.

It gives me hope because without music, I don't know where I would be. I'm so sad inside. That playing music. Being with this band. keeps me going.

Importance of having that voice heard

Sometimes I forget how important what we do is, and how the art has this effect on people. in enabling people to have that little moment of not being who they are necessarily, having that little moment of being on a stage and performing and Having that voice, the voice and the power. Because all our bands write their own music. It’s all original stuff. Giving that sense of having a voice heard is so, so important. And the arts, working in the refugee and the side of the system is one of the most important, apart from giving them access to good solicitors and legal advice, The arts has this impact. No other thing can have that same sort of impact. You can let your emotions out, spill out. You can say what you need to say and we support them as much as we have a support worker as well to help with legal cases.

But I feel privileged. I feel absolutely privileged to do the job that I do and to help shape their journey in the music world. And who knows, Glastonbury could be next. If it is, you're all invited! Thank you very much.

CHAT From **Johanne - Hear Me Out** Please visit our **Hear Me Out** website for more music and check out our campaign More Than a Label. Hear Me Out | We help people held in immigration detention through music. This is the link to: The Unknowns live at Union Chapel - full performance - YouTube

Professor Rachel Tribe, chair Thank you, and that was wonderful. I love the name of your organization. It says it all and your enthusiasm is inspirational. So thank you.

Our next speaker is Phoebe Shaw who is the Community Programmes Manager at Artcore in Derby and Coordinator of Untold Stories at their Community Hub where refugees and asylum seekers participate in art activities with the local community. Welcome.

PHOEBE SHAW, Communities Programme Manager, Artcore, Coordinator of Untold Stories Project, Artcore, Derby.

Untold Stories at Artcore Community Hub welcomes people in the local community, including refugees and asylum-seekers and recent immigrants to express their unique narratives through a diverse range of artistic methods. Artcore is a visual arts charity encompassing an art gallery, artistic studios, a shop, and a café.

Phoebe Shaw, Untold Stories

Thank you very much. I will reiterate what everybody has already said and a great thanks to Veronica for inviting me to speak today. Listening to everybody else speak has been really fascinating. I am Phoebe and I am the Programme Producer for Artcore and we are based in Derby in the UK.

We are a visual arts charity. We have a contemporary art gallery as well as a community hub. And we host exhibitions and residences from our gallery; and we deliver a range of creative arts workshops from our community hub for our diverse community in Derby and beyond.

Together we Stand

Our statement *Together We Stand* summarizes how we really want to engage and connect with a diverse range of communities. Our key objective is to use as a tool to strengthen community cohesion to educate, raise awareness and provide space to build self-confidence.

Creative arts for refugees and asylum-seekers, Bosnian and South Asian Communities.

These slides are part of our Untold Stories project which is funded by the Baring Foundation. It focuses on working with recent immigrants and refugees and asylum-seekers and members of Derby's Bosnian and South Asian communities.

Storytelling using art as universal language

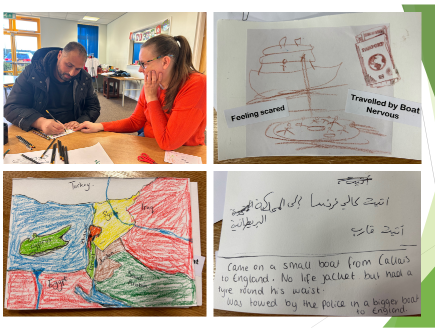

Untold Stories Project

We are delivering a programme of workshops which invite local communities to share their stories through engagement with creative arts. Working alongside professional artists, we have developed a programme of workshops that highlight the importance of using art as a universal language – to break down barriers to communication and to support creativity, confidence building, development of social skills and improvement of mental health and wellbeing.

Something that's really been highlighted to us since we've started this project is how much art can enrich lives and how it can build confidence as well as a sense of identity, and how it can improve that mental well-being and help to interpret the world around us.

These are images from the project so far, and individuals that we've been working with.

Arts workshops for refugees awaiting advice



أتيت كالي فرنسا إلى المملكة البريطانية

أتيت قارب

Came on a small boat from Callais to England. No life jacket but had a tyre round his waist.
Was towed by the police in a bigger boat to England.

We deliver these workshops both from our own community help, but we also deliver outreach sessions at Derby's Bosnian Centre, which supports refugees who have come over from Bosnia, but also it hosts Derby's Refugee Advice Centre, where refugees go for advice appointments. In this relaxed atmosphere, we take the opportunity to offer an additional activity.

In this particular instance you can see the paricipants creating booklets; and in these booklets there is opportunity and the space to draw images - it could be how they're feeling, it could be anything that they wanted to express, but in this particular instance we had an individual share with us how he had made his journey to the UK. Because of the language barrier he was able to communicate with us through these drawings, which was really powerful.

Untold Stories Case Study

I'll just talk briefly about a particular case study that we've had through this project which has been really inspiring. Through these Untold Stories, we've been able to celebrate our participants' individuality. They've been able to find friends and with what many describe as a safe space within our centres. With the freedom to explore art in a fun, warm and inclusive way, many of our participants have found their voice and creative niche.

Poetry and the spoken word to explore feelings

For example, one individual discovered their love of poetry and the spoken word. Then they use that to explore their feelings with their personal life experiences as well. This person tackled difficult subject matter relating to race and equality. But through Artcore, we've had the space to explore these feelings. People have since grown in confidence, form new friendships, explored new techniques in media and that they'd never considered to do before.

Art Connects – a catalyst for emotions and sharing experiences

To summarize, this project has given us many insights, and it has been a pleasure to work on. Sharing lived experiences is so powerful, and creative activities are an ideal catalyst for this. Our Untold Stories project is helping to build bridges and strengths and relationships through greater understanding of life experiences. And using art is a way that we can facilitate recovery and self-expression. Art connects as a catalyst for emotions and therefore sharing experiences; and this is a really powerful thing.

Exhibition at Artcore Gallery 2025

We look forward to curating an exhibition of work produced in the Untold Stories Project, which will be displayed at the Artcore Gallery in early 2025.

Professor Rachel Tribe, chair Thank you very much, Phoebe. That was a fascinating talk. I think a theme that's come across is around universal language through the arts when people don't have a shared language, or culture. So thank you very much

This is our final speaker of this session Kunle Adewale.

KUNLE ADEWALE, is an award-winning Nigerian Multimedia Artist, Curator, Cultural Producer, mental and brain health advocate and arts in health practitioner. Kunle is founder of the Global Arts in Medicine Fellowships and on the steering committee of the World Health Organisation Jameel Arts and Health Lab. He is working in Manchester and has recorded this presentation on the use of creative technologies as artistic support for refugees and humanitarian workers in Sheffield, Bosnia and Dublin.

I'm very excited to join all of you today on World Refugee Day. Today I'm going to be talking about something very dear to my heart, working with the refugees across the world, Virtual Reality (VR) for Refugees' Mental Health. This is a project that I have been working on for quite a long time now.

The aims and objectives of this project is to observe and learn how recreational VR content could support refugees' mental health. And how this technology could be a pertinent tool for wider psychosocial support offered to forcibly displaced persons in Europe, for refugees' mental health, focusing on refugees in the different countries and different locations – these include Sheffield UK, Bosnia Herzgovina, and Dublin, Ireland.

The VR Project provides a recreational experience to refugees who have been victims of humanitarian crisis, the forcibly displaced people. This includes mindfulness and guided dance movement therapy sessions, music, comedy, virtual tours, music, comedy, virtual tour, work in nature - waterfalls, gardens, beach walks, sports activities like table tennis, golf and gaming - and a virtual tour of museums, gallery, heritage sites, even their home countries as well.

It is team-based and this includes nature, space, travel and tourism, sport, music making and dance, art making, relaxation and meditation. We use different VR applications to engage the refugees in these three different locations.

We use Healium, we use TRIPP, we also use YouTube to facilitate this recreational experience for all the participants.

Findings

One of our findings includes this from refugee participants who expressed that the five to ten minutes using the headset took them away from the struggle, fear and the pain they are experiencing in

their refugee journey. They also expressed that this experience will stay with them as it was completely new to them and they felt very lucky to be able to access this technology. All of them share that they would like to do it again and they will recommend others too try VR, to have a good time, play again and experience something unique.

Here is a testimony from another of the participants today: She said,

I used to play golf back home but since I landed in Ireland, we are confined in these small rooms with new recreational spaces. I have developed a knee problem. I tried a brisk walk some months ago. It provoked the pain in the knee which I have never experienced before.

Since I stopped my physical activities. I've been diagnosed with sugar diabetes, hypertension and all of these in addition to the surgery, for which I'm awaiting an appointment next month.

Today, I felt like I was taken back home. When I was playing this game virtually. The next step was that go focusing on one particular city in the United Kingdom, which is Sheffield.

XR Hub for Refugees in Sheffield

The next phase of that is the XR Hub for Refugees in Sheffield. The aim is to serve multiple purposes. Facilitating narrative shift, providing therapeutic support, digital skills acquisition, offering social and economic assistance, advocating for refugee rights and delivering collaborative learning initiatives.

Our target audience are refugees and immigrants and asylum-seekers between ages 15 to 60 for their support. For the idea to be able to activate VR for refugees mental health and for more collaboration and partnership on the next phase of our project, which is the XR Hub for refugees in Sheffield.

Professor Rachel Tribe Thank you very much, Kunle. Another excellent presentation.

PANEL DISCUSSION – chaired by Professional Rachel Tribe

RT, chair I am going to make a comment about a couple of themes and then if anyone wants to come in from the panel, they're very welcome. I think some of the themes for me that were important were about the importance around

- Documenting cultural heritage.
- Importance of co-production.
- Lived experience – led. We've all talked about how, or we all know some of us more than others about experience when things are done to people are offered to people without actually listening to the people that are having things done to, who are actually the experts by experience and should be the ones in the driving seat.

- Academic language - the other thing that came to me was the importance of thinking about what is called in academic language, Cartesian dualism, which is when we think about how the body and mind interrelate. I think in the West we tend to differentiate far more than we should do and I think you've all shown how the two are so connected.
- The Soul - I would also add into that mix the importance of thinking about Soul or whatever word we want to add there.

I don't know if anyone wants to add anything. I just want to thank an excellent panel. I've learnt so much and hope to be in touch with all of you.

Johanne, Hear Me Out I think I'll take your first point.

Co-creation

We have started really thinking about co-creation and how we all work together and who all our stakeholders are. We do have a group, a co-creation group, and that's made up of staff, board members, those with lived experience and artists as well. Anybody that has anything to do with our organization involved in this co-creation group.

Language inclusivity

What I found really interesting the other day in our meeting was Kuaku who sang *Hope to Humanity*, brought up a really interesting point just in the way the language that we use like the word ‘neutrality’ and what it means to him and we're putting it in a document, then we need to explain what that means and also non-biased. So we found working with refugees and asylum seekers and our artists all as one. We've got a better understanding on what the organization is able to do and how we should do it to make sure that everybody feels included. We completely understand that it's the people we serve, that's who we need to find out. How we can serve them best with what we do.

RT, chair Thank you, Jo

Sara, A.R.T. I would like to make one point, which is: Most of you probably know that the majority of work being done for refugees is very much a top-down process We come in, we give them what they need, they become dependent upon us. What my organization was started for was the reason that - I believe all of you as well hold this belief - that if you empower people themselves, they can heal themselves; and they can create a better future because it's within all of us. It's just a matter of giving them back their dignity and encouraging them to know that it is within themselves that they can rebuild. So it's a very important point to notice that there has been a **shift in** aid relief in work with refugees, and it becomes much more of a bottom-up process. I think that when we can give and empower. them, they can do the rest.

Thank you, Sara.

CHAT Veronica, host : In our preparatory chats, Hear Me Out and Music Action International were keen to get together - would you like to talk more? V
Johanne - Hear Me Out : I'm happy to talk about it
lis murphy, music action int Hi, yes we have a meeting booked with John CEO, would love for Johanne to be there too and talk ideas for collaborative grand tour! Music Action International Youth Music 2023 evaluation

Veronica There was an issue that I was really keen to raise. That is acturally the reason for no delegate questions was because, I believe, the two music groups are keen to collaborate; and I wondered if just before we close you would like to expand on this, because you mentioned it in our preparatory talks – and it was so exciting!

Johanne, Hear Me Out

Potential partnership with MAI Crisis Choir

Yes. In brief, we're just putting together a three-year project plan, looking for funding from the Arts Council and other organizations. It's about how we empower our bands and those who are making music. One of the things that we want to do is – I'm very into working with different organizations and partnerships - We would love to work with Music Action International and your Crisis Choir because we believe that you will elevate what we already do - and the possibilities. We want you to come to all of this in 2026. Thank you.

Veronica, host Well, this is brilliant. We will put you all in touch.

Ramsey, MAI Crisis Choir

Need for Society to understand refugee's dignity

I just had one point out, going to the point about caution with language. Just one point, which isn't to really criticize or shame or anything, but I think often society thinks our role is to give people dignity and power, but they already have that. I think our role is really to get society to realize that they're not recognizing that. It's not something we're giving to the people. It's something that we need to shift socially and politically. But I understand that those words can just be a shortcut to the same thing.

Sara, A.R.T. Just to clarify. My point was that within us, we all have that dignity. It was to empower them to know that they have it within themselves.

Veronica, host It's really interesting this dialogue. I do wish it could go on for longer. There was another question about whether you use interpreters or not. And there have been so many different approaches, I'll say this later, but I'd like to have a follow-up one because that we need longer time to talk.

I should like to thank you, Rachel, for your brilliant charing, your wise and knowledgeable chairing and thank you to all, to our excellent speakers and to Sara from coming – even with laryngitis. You have been totally brilliant. Thank you all very much.

Now, I should like to reintroduce Alex to chair our final, academic drama for refugees partnership programme.

PROJEKT EUROPA's Academic Partnership Programme PROJEKT ENCOUNTER

Chair: Alexandra Coulter, Director, National Centre for Creative Health

Thank you, Veronica, and thank you to the previous speakers all totally fascinating. We are going to move on now to another group of speakers. They all work together PROJEKT ENCOUNTER. I shall introduce them all at the beginning and then they will each talk for about five minutes about their roles in the PROJEKT and at the end there will be a brief film. The speakers are Maria Aberg, the Artistic Director of PROJEKT EUROPA, which is the host organization for PROJEKT ENCOUNTER.

MARIA ABERG, is an award-winning director, writer and the Founding and Artistic Director of PROJEKT EUROPA, an artist collective, advocacy group and arts organisation creating migrant-led work at the intersection of performance, co-creation and participation. She has made work for venues including the National Theatre, Donmar Warehouse, Royal Court, Dramaten and Staatstheater Mainz. She has been an Associate Artist at the Royal Shakespeare Company since 2017 and has directed over ten productions there, including As You Like It, The Duchess of Malfi and King John. Her current practice sits between participation and performance, working with migrant artists to explore notions of identity, locality and the juxtaposition between personal and collective history. By working multilingually she actively challenges the colonial assumption that underpins the dominance of the English language, and as a result her work is often choreographic, focusing on the imperfect body as a site of knowledge and experience and the physical/visual as the central gesture of expression.

Maria Aberg, Artistic Director, PROJEKT EUROPA.

Thank you so much. I want to start by saying what everyone else has said is that it's a massive privilege to be here and to share a space with so many practitioners whose work I really admire. So thank you, Veronica, for inviting me.

I want to give a little overview of the company contextualized that this PROJEKT ENCOUNTER that we run, and that Francesca and Angie will discuss.in a minute.

I'm the founder and artistic director of PROJECT EUROPA. We're a small charity and arts organization and a theatre company that makes work for by and with first generation migrants at the intersection of performance participation and cooperation.

At the heart of our activity is the conviction that everyone can be an artist and we offer a definition of an artist as *Anyone who pursues a creative endeavour over time with joy and rigour.*

We're a migrant that organization, which means that the leadership team, the artistic advisory board and the board of trustees all have lived experience of migration. All our activity is focused on supporting the creativity of first-generation migrants, refugees and asylum-seekers in the UK, amplifying marginalized voices and celebrating the multitude of international perspectives which exist within our borders. The work that we do breaks down roughly into three areas which all overlap and intersect.

Artist development

The first one is artist development. We work to support migrant theatre makers to improve industry access and give them opportunities to thrive in their careers. For example, we run a mentorship scheme where we pair up emerging migrants theatre-makers with senior or established migrant talent and support them to build networks and to improve industry access for them at the beginnings of their career.

Regional theatre partnerships: commissions for more established migrant artists

We run micro commissions in partnerships with regional theatres around the UK where we pay more established migrant artists to develop ideas for co-created work together with local communities, which serves both as a way of developing work that's grounded in place, but also to forge relationships between migrant artists and leading cultural organizations around the country.

Practice Lab for migrant theatre makers

We run a Practice Lab, free skills exchange programme for migrant theatre makers.

Community Engagement, including PROJEKT ENCOUNTER

Our second area is what we might call community engagement, for want of a better term. And this is where project encounter sits. This activity is for people who have little or no previous experience of taking part in cultural activity.

Audience facing

The third area is our audience facing work – productions or exhibitions or anything that really happens in front of an audience.

As an example, last year during Refugee Week, I directed a project called, *Let your Hands Sing in Silence* that was co-produced with the Marlow Theatre in Canterbury – that was performed by an ensemble that was a mix of community performers that had come through PROJEKT ENCOUNTER and professional performers.

A project we're developing this year is called *Desire Maps*, which is an interactive map-making performance, where we invite audience members to reimagine the geographical journeys of their ancestors - it looks at climate migration and the intersection between personal history and global events.

International

In addition to all of this, we've also recently started collaborating beyond the borders of the UK. For this year's Refugee Week, we have helped to curate an exhibition of work this facilitated by a grassroots NGO in Lebanon called the Araqa Collective. It is an exhibition of text and images created by Palestinian and Syrian refugees and young Lebanese people .that's exhibited at our base, which is Ark Cliftonville in Margate, which is a community art centre in Margate.

We also organize and conversations a little bit like this one, inviting international arts organizations and artists to talk about topics such as co-creation with communities or place making and festivals.

So that's a little snapshot of what PROJEKT EUROPA does.

Alexandra, chair Thank you very much, Maria. That's brilliant. That gives us the context for hearing now about the project itself, PROJEKT ENCOUNTER. I'd like to invite Dr. Francisca Stangel to come and talk now.

DR FRANCISCA STANGEL is PROJEKT ENCOUNTER's Drama Workshop Director. Originally from Sweden, she is a clown, theatre maker and applied theatre practitioner. Her passion for working with young people and marginalised communities led Francisca to co-create performances with refugees, asylum seekers and migrants, as well as with organisations such as Clowns Without Borders UK. She is a company director of award-winning Acá Theatre who make witty and slapstick-tastic performances for young people, and works as a freelance performer, director, producer and facilitator. With a PhD in Elizabethan drama, Francisca is a guest lecturer at the University of Kent, and frequently facilitates workshops in clowning, ensemble, LAMDA, classical theatre and physical theatre.

Francisca Stangel, Drama for Refugees workshop facilitator, PROJEKT ENCOUNTER.

Thank you so much for inviting me. This is a really wonderful symposium and thank you for championing all this work of all these fantastic people.

PROJEKT ENCOUNTER is a twenty-week drama workshop programme that engages with migrants, refugees and asylum-seekers based in Kent. We've just concluded the third iteration of the project this week – we met on Monday for our evaluation session.

Napier Barracks

Each project has collaborated with Napier Barracks that we heard a little bit about before. It's a refugee and asylum centre in Folkestone with men over the age of eighteen. They spend around seven to eighty days there before they get moved on to different housing – that could be anywhere in the UK. They are very much in a situation of transit and waiting.

Platform for Connection and feeling of Togetherness – and stress relief

The aim of the workshops is to provide a platform for a connection and a place for what Cornelius spoke about, this feeling of togetherness. It's also an opportunity to connect and reconnect with your creativity. The participants have told us in our evaluation sessions that for them it is also an opportunity to experience some stress relief and to build confidence in in the English language, as well as team building and public speaking.

Overcoming language barriers

We work with interpreters. But also work with a lot of non-verbal activities such as games and physical theatre to overcome language barriers.

Theme for 2024: *What is Change? What is Transformation?*

Each project centres around a theme and this year the theme was '*What is change*? and '*What is Transformation*? Because we all as migrants share this fact that we've gone through this big change of changing home, from one to another. So together we interrogated what is change and what is transformation over this twenty-week PROJEKT. This is normally divided into four phases:

Creating an inclusive space:

The first phase is about creating an inclusive space, a safe zone and to build a foundation of the work that we then carry on with.

Devising and exploring more theatre practices

The second phase is about devising and exploring more theatre practices and getting more confident in using them and working around the theme of the PROJEKT.

Working towards a performance

Then the third phase is about working towards a show, a sharing for an invited audience, where the participants also get an insight in how it is to set up a production. We have a technical team, we have stage managers, we have lights, costumes, all of that.

Evaluation Session

The fourth phase is the evaluation session. The show became a celebration of change. It stemmed from an exercise where each participant plotted on this long piece of paper, cultural events from their background, things that they've experienced in the culture they have come from, and they celebrate. What became clear is that most of us in the room, and most of the cultures we have experienced, celebrate these transformations of change, whether it's a change of government, like independence days or whether it is a change of seasons or New Year. Most cultures had some kind of big celebration with dance, food and coming together.

The performance reflected that, in that it culminated in a big celebration with dance and music. We manipulated this big piece of paper to create a fire that they danced around. It was really lovely.

Magic of connecting across cultural barriers

What becomes apparent from these workshops, is this magic that happens when we as humans come together, and the willingness to connect across language and cultural barriers. I think that this willingness is also something that strengthens the connection really ,because you have to work around even if you work with interpreters there's a lot of patience, a lot of understanding and curiosity about each other's cultures. It is something that has been really, really magical to experience in the room.

Alexandra, chair Thank you so much, Francesca. That's wonderful. And this some of these themes will try and pick up at the end around around language and connection, but also the the artistic development which I can hear is very much an important part of your of your company.

PROJEKT ENCOUNTER FILM

My name is Francisca Stangel. PROJEKT ENCOUNTER is a collaboration between PROJEKT EUROPA and the University of Kent. We are leading a 20-week community drama programme for people with a migrant background - it can be people who have been here for 25 years or someone who arrived last week.

We have done this PROJEKT three times and we have worked for all three projects with Napier Barracks, which is based in Folkestone ,which is an accommodation centre for refugees and asylum-seeking men over the age of eighteen. They stay at this centre for 70-80 days and then they get transferred somewhere around the UK. You have people who come here via the small boats and who are, I guess, lucky enough to make it over. But also have witnessed people who haven't made it over, so you get all of those scenarios and sometimes they pop up during the sessions.

Drama – as community activity, not therapy

We're not doing drama therapy, but we want to provide a safe space to explore these things.

Participant *This place helped people feeling people feeling human, and just received this energy kind of energy and support that they don't give up because it was with me.*

Francisca There's something really lovely that happens in between the words when we don't rely on the same shared language and we find similarities in other ways.

Participant: *The interaction with other guys is amazing. Because in the beginning for me I thought you would be very very difficult. When you can't understand each other is very very hard but I'm so surprised it's easy. We understand each other. Then I really love it.*

Francisca That's a really lovely thing for them is this connection with other people. I think for the participants who come from Napier specifically they often talk about the excitement of leaving camp because they are in this camp for very many days. I feel really fortunate to be a part of this project. It's very life-affirming.

You get so much joy because the participants bring so much joy and you are often floored with the generosity of spirit that they bring and It makes me Remember why theatre is so powerful and important.

Participant *I can say that this project has changed a lot of my life, to be honest.*

Alexandra, chair Our third speaker is Dr. Angeliki Varakis-Martin. She is from Kent University. So this brings in an academic perspective on this programme

DR ANGELIKI VARAKIS-MARTIN has worked at the Drama Department since 2007 as a Lecturer in drama and is responsible for coordinating the international exchange programme. She has ongoing research interest in the work of Greek theatre director, Karolos Koun and his contribution towards the creation of a modern Greek tradition in the staging of Greek theatre. She's exploring the applicability of various acting techniques to Greek theatre with a special interest in masked acting. I think that comes out, doesn't it, in this program? I'll hand over to you now, Angeliki.

Dr Angeliki Varakis-Martin, Lecturer in Drama & Theatre, University of Kent

Thank you very much. I'm coming more from the university side of things and I wanted to say that this year and for the first time PROJEKT EUROPA has chosen to run their community workshops on a university campus. We are grateful that they've chosen the University of Kent to do so. Because through our collaboration with PROJEKT ENCOUNTER and their work with refugees, we see and we saw the immense potential that exists in linking research, teaching, and initiatives to higher education's civic mission and to create a model of community work where arts education, academic research and student experience informed by external engagement, such as volunteering and work experience, helps build bridges with vulnerable communities that are most in need of our support, such as refugees. Hosting PROJEKT ENCOUNTER on our campus and within our institution seemed to work, well on many different levels.

The PROJEKT gave the opportunity first of all for university staff, students and refugees to interact and bond within a creative and entirely democratic non-hierarchical context for a project which places refugees centre-stage, celebrating their cultures and languages,

Academic range of arts and education– most from migrant backgrounds

Hosting the project within our university meant that most of the support came from our student community, who brought with them their expertise and knowledge. Students came from various arts and humanity subjects and were at a different level of their study. They came from film and media, drama, and they acted as design assistants, stage managers, light and sound technicians, film crew, film editors, production assistants, interpreters, translators. And, of course, our students gained valuable work experience through their active involvement, but this time in a meaningful and impactful project.

Giving refugees opportunity for further arts study

At this point it is important to note that most of our students involved were from a migrant background themselves; and in this respect were particularly sensitive and attuned to some of the topics that were addressed in the workshops and which had to do with being away from your country of origin, celebration of course of different cultures and languages and being a non-native speaker. Another really important aspect to it, hosting it within the university is that we found that it helped raise awareness within the refugee community about the opportunities to pursue further studies to study art subjects.

Building academic relationships

Participants were able to build relationships with staff and students, find out more about university life and opportunities to further their studies through conversations that occurred during our short breaks before or after the workshops but also walking and dining on campus.

So this less formal interaction in conjunction to the fun atmosphere of the workshops inspired many of the participants to think about studying drama and film, but also made them more open to sharing their desire to further their education, because the academic environment appeared as a welcoming and friendly place – sometimes it could be intimidating when you're thinking of applying.

A result of this PROJEKT is that we're very happy to share the news that we already have one application from one of the participants to study drama at Kent. But we've also had other participants that are interested. They were very inspired by the work of Francisca, by the workshops in the performance itself. They have shared that with us. I think that was great.

Participatory research project

Finally, and in addition, this series of workshops has initiated a participatory research project. that was funded by the university, whose funds helped support PROJEKT ENCOUNTER. In this project all participants, the refugees, first generation migrants who ever participated are acting as co-investigators in order to explore the ethics of working with and as part of a multilingual group of first-generation migrants and refugees in an applied-theatre context.

Film essay

The output will be a film essay where all participants would have contributed – those who have agreed, of course – through reflecting critically on their experience. The aim is for their views and thoughts, some of which are in the form of short self-recordings. They are making the film as well to help inform best practice for future creative projects that are similar. The film will be credited to all those who participated in the making of it. So all our participants have been performers, but they're also researchers.

PANEL DISCUSSION – Chaired by Alexandra Coulter

Alexandra, chair That's wonderful. I think that's really fascinating, because I think one of the things that comes out of all of you speaking is the sort of *What next?* question,

What is the legacy”

What next? What is the legacy, how does this work? What are the ripples of this work? I think that I'm right in saying that the work isn't finishing with this third phase, but I know for all projects the ongoing issue of getting more funding and so on means that it is likely to have to finish at some point. But as I understand it, also some of the participants are still in contact with you from previous phases. There's some peer-to-peer support that happens. I am interested in you all reflecting on what you see the future of this project being.

Maria I think connected to something that Almir was saying really early on in those conversations this afternoon, about trying to tailor it to each individual. That I think is largely what we try and do. But as an example, there are several participants from our first round of PROJEKT ENCOUNTER in 2022 who are now members of our Artistic Advisory Board, so they're still deeply engaged with the organization.

Several of the past participants also took part in this project that we produced last year during Refugee Week at the Marlow Theatre where they were performing in a different project. So the legacy of people continuing to engage with the organization in whatever way they like or whatever way is appropriate for them is really clear.

Francisca Keeping in touch - peer support through PROJEKT WhatsApp network

Something that's really lovely has happened in that, in the first iteration of the project that they began – it was participant-led – this WhatsApp group has grown over the last three years and has, I think over 200 members. This means that there is a network now of that peer support. We also find that when especially people from Napier Barracks get transferred, either we can link them with other people who have transferred, or we can link them to other arts organizations. Or sometimes they even come back and visit. We had a participant who was part of the very first project who got relocated and made their way to London and is now working in London. He came to visit and participate in one of the workshops and I think that network and also connection for the newer arrived participants to see that there is a future if you like, is something that is quite lovely.

Alexandra, chair Yes, brilliant. Angeliki, do you want to say anything on that question?

Angeliki I think it's, fascinating how this, series of workshops creates a real true bond between the people and even if you have been or haven't you're still part of that community and that it's almost ongoing.

A family that continues to grow

It seems to me when the participants did come to talk to us from previous performances and workshops, they felt that they had this responsibility to come and to talk and to share. They were perfect role models and something to aspire to. So it's a family that continues to grow, I would say. One of our participants that had this recommendation that we should make a big poster in their evaluation where we all write and this gets bigger and bigger and bigger about our experience as part of these series of workshops that happens every year - and hopefully will continue to happen for years to come.

Alexandra, chair That's fantastic.

Language and interpreting

I do have another question around language - that has come up a lot today, around and obviously the non-verbal communication that one associates with performance and music and so on, and whether or not people use interpreters. I get the impression that the groups you work with have many languages – you're not usually working with a single language group, are you, so is there anything about that that you would like to reflect on?

Maria I think, like Francisca said, we do both.

Non-verbal communication and interpreters for inclusivity and confidence

There's both non-verbal activity and communication and we've got one or two interpreters per session. One of the reasons that we did that, I suspect, was because we all have lived experience of being the person in the room who doesn't feel confident with the language. And what that does is that it often puts you on the back foot. It often means that you might not participate as much as other people, you might not feel as confident to speak up. I think we all know what that feels like. So I think for us it was also important to make sure that if people don't have the confidence to speak up, or don't have the ability, that there is someone else in the room, we can do that for them.

Angeliki Francisca, do you want to say something?

Liberating Use of Masks

Because I was going to mention how fascinating it was when they worked with masks, which were silent, so no language needed. They really came out of their shell and they became super expressive and less self-conscious because it didn't matter anymore. I think that came out in the feedback that they really liberated them in a way. One side of it – this is the silence - didn't matter anymore; and also the fact that, as the workshops progressed and we had bonded more, or those that were there for many workshops, it seemed to me that it didn't matter, that gestures were enough. I thought that was really wonderful.

Alex Building Trust

I was just going to say that which came up earlier, that question of building trust, which is so critical, isn't it?

Francisca

Huddling together over a Google Translate phone - connectivity

Well, it was just to say that, it's something very bonding when you have to huddle over a Google Translate phone to try and work out what it is that you want to say alongside gestures and the rest. So I think what looks like barriers might actually be conductors for connectivity.

Alexandra, chair That's a lovely end. So that's fantastic. Angeliki, the evaluation or the research film will presumably be available in due course. So thank you all very much. That was really a wonderful introduction to your collective work. And I'm going to hand back to Veronica now to end the whole event.

Veronica, host Thank you very much, Alex, for your tremendous chairing of the event has been such a privilege. And to the whole PROJECT EUROPA PROJEKT ENCOUNTER team., I was keen that you should have a bit of time at the end because of the academic legacy of your work. Indeed all speakers' programmes are ongoing, life-enhancing and vital for refugees – Warmest thanks and congratulations to you all for sharing your inspirational work. It's been a real privilege to host and raise awareness of such life-preserving, thoughtful, cross-cultural practice.

I just felt that at a time of strife and conflict and all the awful things that are and have been going on, it would be valuable to show the amazing opportunities you open up. It's amazing of you all to come and speak and listen. Thank you so much.

CHAT

Sunny :This has been brilliant, thank you so much everyone. I've got so many notes from so many different groups/orgs and people! I work for two charities, Music in Hospitals and Care, and Voices in Exile. I thought you may want to check this out: https://www.youtube.com/watch?v=R1IckxJ1IL0 This soundscape serves as 'representation' of my experience living through the six stages of PTSD following the 2020 Beirut blast. Through original and recreated sounds of the time! I hope it's informative in some way.

Beatrice Vegas : Immensely useful webinar . Thank you Veronica and everyone who have made this informative webinar possible.

Daniela Nofal | Counterpoints Arts Thank you so much for hosting this and inviting us to be part of it,

Sara Green :Reacted to "Thank you so much Ha..." with ❤️

Sheila Hayman : such an absolutely inspiring bunch of people and projects. Thanks!

Hanan Khalil Thanks so much Veronica for the invitation and for fantastic webinar. It is a great learning experience to me.

Sheila Hayman :So much inspiration in a short time; what a fabulous Refugee Day, thanks everybody.

Lis Murphy, Music Action International:Amazing group of people, thanks so much for organising and inviting us Veronica!! xx

Ramsey Janini :Thank you everyone !

Ruchira :Thank you all....

Maria Aberg (she/her) PROJEKT EUROPA Thank you so much - what an incredibly inspiring afternoon!

Ryn Delpapa : Great job, it was beautiful witnessing the film and taking part in today's summit. Thank you @Veronica Franklin Gould

Angeliki Varakis :Thank you!

Francisca Stangel Thank you so much for Veronica for organising, to Alex who chaired and to all!

RESOURCES - World Refugee Day Conversation

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El Alaoui-Gars, M, 2022 *Neurology in Migrants and Refugees*.

Garry F. and McFarlane A., 2023, 'A scoping review of the use of music as an arts-based method in migrant health research' *HRB Open Res* 2023, 6:74.

GBHI PT Resources (YouTube)**:** CVT Physiotherapy Services Awareness; Progressive Muscle Relaxation; Posture and Ergonomics; Body Scan; Breathing; Mindful Movement.

Global Compact on Refugees: The Acting Project: theatre and refugee integration in Greece, 2019.

Grasser, L. R., National Institute of Mental Health (15 articles).

Greece together promote student art festivals promote refugee integration, 2024.

Kalmanowitz, D. and Lloyd, B. (2005), Art Therapy and Political Violence: With Art Without Illusion, London and New York: Routledge.

Kreidie, L. H., Sakhi, S., et al, '2024, 'The impact of Dramatherapy on the Mental Health of Socioeconomically Disadvantaged and Refugee Women in Lebanon' *Journal of Social Service Research.*

– 2020, 'The Power of Theater Expression and Communication: A Psychological Theraputical Intevention in a Refugee Camp: An IPA Study Into the Narratives of Women Refugees' Experience with Drama Therapy, 2020, Psychology Research, Van 2020, Vo. 10. No. 1, 10-23.

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Lloyd, B., Press, N. and Usiskin, M., 2018. 'The Calais Winds took our plans away: Art therapy as shelter', Journal of Applied Arts & Health, 9:2, pp. 171–84, doi: 10.1386/jaah.9.2.171_1.

Skyme, S., and Hogan S., 2023, What are the Affordances of Arts-Based Workshops with Refugee Women and Girls?', *Creative Arts in Education Therapy* January 2023, 8 (2): 173-184.

Tribe. R., and Raval, H., 2003. *Working with Interpreters in Mental Health*.

Usiskin, M., Lloyd, B., & Press, N. (2020). Temporary, Portable and Virtual – making galleries on the France-UK border at Calais in Art Therapy in Museums and Galleries. Jessica Kingsley.

World Health Organisation Refugee and Migrant Health Toolkit, 2024.

World Health Organisation, European Region, 2022 Arts and health: *Supporting the mental well-being of forcibly displaced people* (includes 38 resources).

Write to Life Zines.

SPEAKER BIOGRAPHIES

MARIA ABERG, is an award-winning director, writer and the founding and artistic director of PROJEKT EUROPA, an artist collective, advocacy group and arts organisation creating migrant-led work at the intersection of performance, co-creation and participation. She has made work for venues including the National Theatre, Donmar Warehouse, Royal Court, Dramaten and Staatstheater Mainz. She has been an Associate Artist at the Royal Shakespeare Company since 2017 and has directed over ten productions there, including As You Like It, The Duchess of Malfi and King John. Her current practice sits between participation and performance, working with migrant artists to explore notions of identity, locality and the juxtaposition between personal and collective history. By working multilingually she actively challenges the colonial assumption that underpins the dominance of the English language, and as a result her work is often choreographic, focusing on the imperfect body as a site of knowledge and experience and the physical/visual as the central gesture of expression.

KUNLE ADEWALE is a Multimedia Nigerian award winning International Artist, Curator, Cultural Producer, Mental and Brain Health Advocate based Arts in Health Practitioner based in Manchester, United Kingdom. Kunle is a Global Atlantic Fellow for Equity in Brain Health and the founder of the Global Arts in Medicine Fellowship. He is a certified artist in Understanding Arts and Dementia (University College London, UK), Medicine and The Arts, Humanizing healthcare (University of Cape Town, South Africa), Psychology and Mental Health, Beyond nature and nurture, University of Liverpool, Effective Fundraising and Leadership in Arts and Culture, University of Leeds, UK. Kunle leverages the use of creative technologies and art engagements to support the brain and mental health of refugees of persons in Nigeria, United Kingdom, Ireland and Bosnia. He is a steering committee member of the World Health Organisation Jameel Arts and Health Lab established in New York University.

KAY ALLEN OBE FCIPD FRSA is Campaign Director for Age Irrelevance. Previously Kay's career included Royal Mail Group, BSkyB and B&Q, her work has focused on change management, customer solutions and employee engagement. Previously Kay has served as a Commissioner on both the Disability Rights Commission and the Equality and Human Rights Commission. She has over thirty years' experience in supporting strategic partnerships between corporates and social enterprises looking for innovative solutions that have a positive impact on society. Kay is a Fellow of St Georges House Windsor.

CHRISTOPHER BAILEY is the Arts and Health Lead at the World Health Organization and a co- founder of the Jameel Arts and Health Lab. The lab focuses on the evidence base for the health benefits of the arts by building up a global network of research centres to look at effective practice as well as the foundational science of why the arts may benefit physical, mental and social wellbeing, to support underserved communities around the world. Through its Healing Arts activities, the programme also engages with the global media to promote pro-health messaging and build solidarity on health issues through all media. Educated at Columbia and Oxford Universities as well as the American Academy of Dramatic Arts, after a career as a professional actor and playwright, Bailey joined the Rockefeller Foundation as their Research Manager, and from there was recruited to WHO where he lead the Health Informatics work and later their on-line communications team before starting the Arts and Health programme. As an ambassador for the field, Bailey has also performed original pieces such as Stage 4: Cancer and the Imagination, and The Vanishing Point: A journey into Blindness and Perception, in venues around the world, from the Hamwe Festival in Rwanda, to the Wellcome Collection in London, to the World Bank in DC, as well as Lincoln Center in NY, the LA Opera, LACMA, and Warner Bros Studios in LA, and the Conservatory of Music in San Francisco, The Metropolitan Museum of Art, the Budapest Opera and the Kennedy Center among many others. The basic message of his work is to amplify the WHO definition of health which states that health is not merely the absence of disease and infirmity, but the attainment of the highest level of physical, mental and social wellbeing.

MONICA BOULTON is the Healthcare Integration Lead for the National Academy for Social Prescribing and a Non-Executive Board Member for Musical Walkabout CIC. Monica has been involved in Social Prescribing for nearly 10 years after her Music degree confirmed her passion for how important the creative arts are for people with Dementia. Having worked as a Social Prescribing Link Worker and managed multiple social prescribing projects, and volunteered as both a SPLW Manager's champion and national expert for the National Association of Link workers, Monica has a true sense for the difference Social Prescribing can make not only to people's lives but to the health system and communities too. Monica is passionate about community development, and has extensive experience in the voluntary sector alongside providing some Social Prescribing System consultancy work.

CHRIS & ANDREA CHADBURN Since 2021 Chris has been living with a diagnosis of logopenic variant Primary Progressive Aphasia, a rare form of dementia which presents challenges with language and speech. Both Chris and Andrea include the arts into their daily lives through painting, drawing, sewing and poetry. Andrea has always been creative and often works with watercolours. Artmaking is a relatively recent endeavour for Chris but he particularly enjoys painting pictures of buildings and making cards for friends and family. They love gardening and cooking together and having just celebrated their 50thwedding anniversary, they are determined to continue living life to the full.

RACHEL CHEN, Founder and President of the Initiative for Social Prescribing at Harvard University, Cambridge, Massachusetts, USA and NASP Visiting Collaborator. As Research Assistant at the Center for Geriatric Medicine in Cleveland, Ohio, Rachel is building the infrastructure and partnerships for a new social prescribing pilot and designing an original research protocol to evaluate the programme's impact on geriatric patients. She was awarded Joey Hanzich Memorial Fellowship to support work on this project.

DR BOGDAN CHIVA GIURCA is a medical doctor leading the Global Social Prescribing Alliance, which was launched in 2019 in collaboration with the World Health Organisation and the World Health Innovation Summit. The Alliance currently consists of international leaders from over 32 countries worldwide. Bogdan has played a key role in the development of Social Prescribing in England since 2015 through establishing and chairing the NHS England Social Prescribing Champion Scheme (2015-2023) consisting of over 20,000 doctors, medical and healthcare related trainees championing the subject in their own institution. Bogdan lectures at Imperial College London (leading the Social Prescribing module), is an Honorary Lecturer at University College London, a Collaborator for the Harvard Global Health Institute, and is named among the ‘Top 100 Most Influential People in Health’ in the UK (Health Service Journal Top 100, 2022).

HELENA & DAVID CLARKE Helena was diagnosed with Posterior Cortical Atrophy in 2020, after having originally been told she had a visual impairment. Over the past 3 years, Helena and David have engaged in a series of creative projects alongside RDS including being involved in the development of the Rare Space Garden designed by Charlie Hawkes, which achieved a gold award at RHS Chelsea Flower Show 2023. Helena is an artist in her own right, making drawings and paintings which reflect on and adapt to the challenges of life living with PCA. Helena and David incorporate creativity into their lives in several ways, whether it be rewilding their garden, cooking improvised soups, swimming in the sea or visiting cultural venues together.

ALEXANDRA COULTER has been Director of the National Centre for Creative Health since it launched in 2021. She was Director of Arts & Health South West (AHSW) from 2010-24, providing the secretariat for the All-Party Parliamentary Group (APPG) on Arts, Health and Wellbeing. She project managed the APPG’s two-year inquiry which led to the publication of the *Creative Health* report in 2017. AHSW delivered three Culture Health and Wellbeing International Conferences and along with colleagues in the field helped set uptake Culture Health and Wellbeing Alliance and the Lived Experience Network, with both the National Centre for Creative Health continues to work closely

PROFESSOR SEBASTIAN CRUTCH is Professor of Neuropsychology at the Dementia Research Centre, UCL Institute of Neurology and is the clinical lead for Rare Dementia Support (RDS). Seb studied Experimental Psychology at Oxford University, before completing his PhD part-time whilst working at UCL and qualifying as a Clinical Psychologist (CPsychol). His research focuses on rare and young onset dementias, especially posterior cortical atrophy, the so-called ‘visual variant’ of Alzheimer’s disease (AD). The work has led to improved understanding of dementia-related visual impairment and the causes and consequences of atypical AD more generally. From 2016-18, he directed the Created Out of Mind residency at The Hub, Wellcome Collection, bringing together artists, scientists and people living with dementia in a collaboration of over 60 individuals, institutions and charities aiming to shape and enrich public and professional perceptions of the dementias, and explore the opportunities afforded by collaborative, interdisciplinary, publicly-situated research.

LE-TIEN DUONG MPH, co-lead of the Canadian Social Prescribing Student Collective, is a PhD candidate in Health Policy at McMaster University in Hamilton, Ontario, Canada. Her interest in social prescribing began several years ago, when she was exploring ways to connect health and social systems. Since then, Le-Tien has become involved in social prescribing through her work with United Way Halton and Hamilton and her dissertation on health systems transformations through community-led social movements.

VERONICA FRANKLIN GOULD founded the charity Arts 4 Dementia in 2011 to develop learning and participation programmes at cultural venues, to re-energise and inspire people above early symptoms of dementia, with website to signpost arts events for dementia nationwide. She worked with Dementia UK to devise training for artists, and with universities to provide best-practice conferences and reports. Her A4D *Reawakening the Mind* programme (2012-13) won the London 2012 Inspire Mark and Positive Breakthrough in Mental Health Dementia Award 2013, and was 2014 Sunday Times Changemaker finalist. On publication of *Music Reawakening* (2015), she was appointed A4D life president. Her regional guide *Reawakening Integrated: Arts & Heritage* (2017) mapping arts opportunities for dementia aligns arts within NHS England's Well Pathway for Dementia. Her social prescribing campaign (2019-23) encourages professionals to empower people to access arts from the outset of symptoms, to preserve their brain health, with practice disseminated in *A.R.T.S. for Brain Health: Social Prescribing as Peri-Diagnostic Practice for Dementia* (2021). Her *Global Social Prescribing: The A4D Arts for Brain Health Debates* involved speakers and delegates from 40 countries around the world. Veronica is trustee of The Amber Trust and Vice-President of Decibels (Music for the Deaf) on the advisory boards of Global Arts in Medicine Fellowships and British Society of Lifestyle Medicine.

TONY THOMPSON & REBECCA GOLDSTONE, co directors of Sweet Patootee Arts, are producers of documentaries and heritage interpretation, bringing inspiring, compelling and diverse stories of real people to an international audience. Over the past 2 years they have been working alongside RDS for their touring exhibition TURNING POINT, a series of four short films inspired by oral histories about the Black Caribbean experience after the First World War. Together with Rare Space they are currently undertaking a knowledge exchange with community groups, arts venues, football clubs and dementia networks to learn more about Black British Caribbean Heritage, share information about rare dementias and generate new creative ideas.

KIRSTIE GOODCHILD, Social prescribing Student Champion Evidence Lead, is studying for MSc in Occupational Health at the University of East Anglia and is the Allied Health Professions Co-ordinator for the 2022-23 Social Prescribing Student Champion Scheme.

GAIL GREGORY 2019 I found myself in a new chapter of my life after I was diagnosed with early onset Alzheimer's at the age of 54. I now live as positively as i can, always looking for something to stimulate my brain. I start my day with an early morning walk with my Scottie dog Toby, enjoying our beautiful local surroundings, helping me create wonderful everlasting memories through the lens of my camera. I believe i need to keep my brain as active as possible. So I focus on the things I can do, like my art, my crafts, blogging, walking and photography. Live life, every moment is precious.

SARA GREEN, Founder and Executive Director of Art for Refugees in Transition (A.R.T.), received her MBA in Finance and Economics from Columbia Graduate School of Business. She holds a BFA in Dance and a BA in History from the Ohio State University. Ms. Green has seven years of experience in management, fundraising, development and strategic planning for non-profit art organizations, including The New York City Ballet and Dance Theatre Workshop. Ms. Green danced professionally for 10 years in Europe and the U.S. In 2011, Ms. Green was awarded the Ariane de Rothschild Fellowship. Her work with A.R.T. has been featured in several books, including *More Than 85 Broads*, by Janet Hanson and *The Art of Doing Good*, by Charles Bronfman and Jeffrey Solomon.

TESSA GUTTERIDGE. Motivated by family experience of dementia, Tessa has focussed on young onset dementia for more than two decades. As the driving force behind YoungDementia UK, the first national charity for young onset dementia, Tessa led the creation of a range of award-winning services. Following a welcome merger, Tessa, as Dementia UK's Programme Director for Young Onset Dementia is encouraging the growth of a range of specialist nursing support and information. Tessa observed the inequity that exacerbates every aspect of the experience of young onset dementia and recognised the different impact of dementia in mid-life. Hence in 2016 Tessa initiated, with highly motivated collaborators including Dementia UK, the Young Dementia Network. With Tessa as its chair, this online community's aim is to improve the lives of people with young onset dementia now and in the future. Tessa believes that everyone should be enabled to live as fully as they can, whatever their disability or circumstances. She continues with optimism and hope.

CHARLIE HARRISON As a visual artist and arts consultant, Charlie co-ordinates 'Rare Space' a new part of RDS which aims to bring together and celebrate the creative and cultural life of RDS members. Charlie has seen first-hand the huge part that cultural activities play in people's lives together and over the past decade he has devised and consulted on a series of research and engagement projects that foreground the creative strengths, celebrate the diverse experiences and highlight the expressive will of people living with these conditions.

SHEILA HAYMAN is the Coordinator of Write to Life, the therapeutic creative writing group at Freedom from Torture. She has held this role for over twenty years, and is proud of its unique status as the longest-running therapeutic writing group in the UK, and the only one for survivors of torture. As the child of a refugee from Nazi Germany who became a distinguished mathematician, she was used from a young age to visitors from around the world, and relishes the mix of cultures in this work. In her other life, she's a documentary filmmaker, writer and journalist. Her films have won a BAFTA, Time Out Documentary Series of the Year, Arts Documentary of the Year nomination and a Robert Kennedy award. She has been UK Young Journalist of the Year, the BAFTA/Fulbright Fellow in Los Angeles, a Hodder Headline Lead Title novelist, Director's Fellow of the MIT Media Lab and a columnist for The Guardian newspaper. In 2020 her work on the carbon footprint of 'AI' led to her being Artist in Residence at PIK Potsdam, Europe's premier research institute on the climate emergency. Sheila is currently on the Board of the Minderoo Centre for Technology and Democracy in Cambridge.

JOHANNE HUDSON-LETT, Artistic Director, has worked as a freelance artist for Hear Me Out for over seven years. For the last 25 years her career has centred around the arts and media. From theatre acting to international marketing, radio presenter for the BBC, UKCCA Carnival participation manager to Senior Producer working to enhance and expand the artistic lives of young people in Luton. Johanne has always been passionate about working with local and marginalised communities as this is the world she grew up in and feels that now is the time to give back. Johanne is also a trustee for the Philharmonia Orchestra, championing our drive to welcome more diverse audiences and players.

RAMSEY JANINI, Creative Producer of Music Action International, is a bass and flute player, finance expert, programme manager and co-facilitates our Crisis Choirs programme in Manchester. He has experience of being displaced by the Gulf War and identifies as being born to a refugee family.

THOMAS KADOR, Associate Professor, Arts and Sciences, and lecturer in Creative Health at University College London, where he leads the MASc Creative Health programme. His research and pedagogical interest include object-based learning, culture, health and wellbeing, public and community-based approaches to heritage. He has lectured and published extensively on all of these topics, including two book books, one (together with Jim Leary) on movement and mobility in Neolithic Europe, and the other (together with Helen Chatterjee) on object-based learning and wellbeing.

CORNELIUS KATONA is Honorary Medical and Research Director of the Helen Bamber Foundation - a human rights charity working with asylum seekers and refugees and Hon Professor in the Division of Psychiatry at University College London. He is the Royal College of Psychiatrists' lead on Refugee and Asylum Mental Health. He is Chair of the Steering Group for the Commission on the Integration of Refugees. He was a member of the Committee that recently updated NICE guidelines on PTSD. He has published more than 300 papers and written/edited 16 books. In 2019 he was awarded the Royal College of Psychiatrists' Honorary Fellowship, the College's highest honour, for his 'outstanding service to psychiatry'.

DR HANAN KHALIL is an Associate Professor of Neurological Rehabilitation at the College of Health Science at Qatar University. She holds a BSc Physiotherapy from Jordan University of Science and Technology and MSc and PhD from Cardiff University. Hanan's area of research focuses on rehabilitation and exercise and related outcome measures in people with long-term neurological conditions, notably, multiple sclerosis, dementia and Parkinson's disease. Further research interests include cross-cultural adaptation and validation of outcome measures in the Arabic language, as well as motor learning and the impact of exercise on improving non-motor symptoms in these populations, such as sleep, cognition and mood. Hanan is also involved in mental health, specifically trauma-informed care for traumatized individuals.

HAMAAD KHAN, a medical student and Global Development Officer at NASP, is dedicated to advancing global health systems with a focus on health promotion and disease prevention. He holds a Neuroscience degree from King's College London and an MSc in Global Health and Development from University College London. Hamaad's research focuses on international social prescribing models. He collaborated with the WHO to author the first global report on social prescribing, highlighting healthcare policy advancements in 24 countries. His goal is to integrate this knowledge into clinical practice, driving broader systemic healthcare changes. Hamaad co-leads the Global Social Prescribing Student Council, collaborating with student leaders worldwide to enhance social prescribing education in health curricula. In 2022, his advocacy against overprescribing in medical education earned him the youngest-ever Hillary International Award for Health & Care Leadership.

NAABIL KHAN, Social Prescribing Champion Global Lead, is a third-year medical student at the University of Exeter in Devon. She raises awareness of the benefits, components, and understanding of Social Prescription within the NHS. As a writer for DYYV, a student-led news site, she is involved with Black, Asian, and Minority Ethnic representation in medical education. Naabil is the General Secretary of Muslim Women in Surgery, where she advocates for inclusion within the surgical field and works to diversify education and awareness surrounding Muslim women in healthcare. She is the President of Amnesty International Exeter, where she raises awareness about human rights violations and discusses social issues with committee and society members.She also co-hosts the podcast Very Junior Doctors.

ALMIR KOLDZIC is Director and Co-Founder of Counterpoint Arts.. The main focus of his work so far has been on developing creative strategies and national networks for arts and refugees; building long term collaborations with leading inter/national arts, cultural, advocacy and philanthropic organisations; and curating and producing a wide range of commissions and programmes relating to displacement, diversity and social justice.

BRIAN LAWLOR is a professor of old age psychiatry at Trinity College Dublin, and Site Director of the Global Brain Health Institute at Trinity. He is a geriatric psychiatrist with an interest in dementia, late-life depression, loneliness and brain health. Brian has worked for over thirty years on developing services and delivering care to people with dementia. His research interests range from early detection and prevention to evaluating new treatments for dementia.

CRISTIAN LEORIN is an adjunct Professor at the University of Padua and the University of Modena-Reggio Emilia where he teaches courses in Assistive Technology and Speech-Language Pathology' and Augmentative and Alternative Communication. He assists the

European Commission as an external expert in the evaluation and monitoring of research projects focused on e-Health technologies for people with disability and dementia. He collaborates with non-profit organizations and public health institutions (including the Italian Ministry of Health and the Veneto Region Health Department) in the co-design of services for individuals with chronic and degenerative conditions and disabilities.
He is the co-founder and Vice-President of Novilunio, a non-profit association dedicated to improving the quality of life and social inclusion of people with dementia and their families.

BOBBY LLOYD is a visual artist, art therapist, supervisor, lecturer and CEO of Art Refuge. She has worked over many years in NHS and community settings, and internationally in contexts of conflict and social upheaval. Through direct programme delivery on either side of the English Channel over the past nine years, she has become increasingly interested in the roles of socially engaged art and art therapy in relation to displacement, crisis support, co-production, community and social justices.

DR WENDY MITCHELL. I was diagnosed with Young Onset Dementia on the 31st July 2014 at the age of 58 years young. Post diagnosis, I was so shocked by the lack of awareness, both in the community and the clinical world, that I now spend all my time travelling around the country raising awareness and encouraging others to speak out in order to reduce the stigma associated with dementia. I am now proud to be the author of the not one but two Sunday Times best sellers, Somebody I Used to Know, and What I wish people knew about dementia, and two Honorary Doctorates. My third and final book, One Last Thing, Living with the end in mind has just been released. Who would have thought that possible nine years ago when I was diagnosed? [Sadly, Wendy died on 22 February 2024].

CAITLIN MUHL BSc MPH, co-lead of the Canadian Social Prescribing Student Collective, is a PhD candidate in Health Quality at Queen’s University. Kingston, Ontario, Canada. Her doctoral work is focussed on social prescribing. Caitlin also supports the implementation and evaluation of social prescribing in her community. Her interest in health quality and public health led her to discover her passion for social prescribing.

LIS MURPHY, Creative Director and Founder of Music Action International, has pioneered the use of singing and songwriting, co-creating programmes with war and torture survivors. She has facilitated skill-sharing and programme delivery with local people in Bosnia-Hercegovina, Georgia, Palestine, Ireland and Sierra Leone.

DANIELA NOFAL is a Producer at Counterpoint Arts., with a particular focus on producing, commissioning and programming artistic projects at the intersection of displacement and mental health. Daniela has been working as a cultural organiser and arts practitioner, and has produced various artistic projects and creative interventions, sitting at the intersection of art, arts education and social engagement. Over the years, she has collaborated and worked with a number of organisations across the UK and internationally, including Beyond the Now, Shubbak Festival and Ettijahat.

CHRIS NORRIS was diagnosed with frontotemporal dementia in December 2012 In the 1970's, he was a musician in the Mounted Band of HM Lifeguards. On leaving the Army, he continued his music and was a founder member of Kent Police Band in 1977.He still plays in Brass Bands and most weeks he can be found playing his tenor horn in concerts somewhere in Kent or further beyond. He was part of a project with Arts 4 Dementia in London where musicians who have a diagnosis of dementia were encouraged to become involved in music making. This was run alongside the English Chamber Orchestra and the London College of Music and proved to be very successful. Chris is an Alzheimer's Society Ambassador and a Kent Dementia Envoy.

PROFESSOR ADAM OCKELFORD is a music psychologist based at the University of Roehampton in London. His research interests include the impact of different neurological conditions on the development of musical abilities in childhood and, conversely, the potential of music to mitigate the effects of neurodegeneration. He has worked extensively with children and young people with Neuronal Ceroid Lipofuscinosis (Batten disease). Symptoms include blindness, epilepsy and the decline of speech, language and swallowing abilities. Adam led a three-year project that examined the potential role of music in enhancing the lives of children and young people with NCL. The use of music in the form of 'micro-songs' was particularly effective in sustaining language when speech itself was no longer possible, and the capacity of music to enable children and young people can engage deeply and meaningfully with family members and friends, even in the most advanced stages of the disease. Sounds of Intent.

KEITH OLIVER lives in Canterbury with his wife and until diagnosed aged 55 with Alzheimer's in 2010 he was headteacher of a large primary school, studying for a masters degree and a primary schools adviser. In 2012 he created the first NHS Dementia Envoy based in Kent. An Alzheimer's Society Ambassador, he has published or contributed to four books about his life since diagnosis, and is currently co-editor on an Open University book series on dementia, inspired by Tom Kitwood. Keith's passion for creativity, borne of his days as a teacher and head teacher of a school recognised by the Arts Council with Gold Artsmark, has remained undiminished since his diagnosis. Whilst frustrated not to continue to play his guitar he writes both poetry and short stories and for the past two years has taken up watercolour painting. In August 2018 he spoke at the United Nations in Geneva about the rights of people with dementia; and has spoken previously at many dementia conferences in the UK and US and beyond, since the pandemic. His activism and vision in the world of dementia was recognised by Canterbury Christ Church University who awarded him an honorary doctorate in 2021.

JAN OYEBODE is Professor of Dementia Care at the Centre for Applied Dementia Studies, University of Bradford, where she is also Co-Director of a Doctoral Training Centre on Transitions in Dementia Care. She is also a registered clinical psychologist. Her current research interests focus on relationships, coping with life with dementia, and family caring, including how culture, age of onset and type of dementia impact on these. Her projects related to young onset dementia include The Angela project (Improving Diagnosis and Post-diagnostic Support for People with Young Onset Dementia and their Supporters) and RHAPSODY (Research to Assess Policies and Strategies for Dementia in the Young). Jan has written both academic papers and more accessible briefings on young onset and frontotemporal dementia. Jan leads the Young Dementia Network Research workstream.

FRANCESCO PARISOTTO, also known as "Frank," is a passionate advocate living with Cadasil, a rare form of genetic vascular dementia. Born in Baden, Switzerland, in 1965, he returned to Italy at the age of six and settled in Bassano del Grappa, in the Veneto, in northern Italy. Frank has worked as a mechanic and a sales consultant for a medical cannabis store. He married his wife Fanny, who has multiple sclerosis since 2010. For over 25 years, Frank has volunteered at the local civil protection association and helped communities devastated by natural disasters. In 2015, after a series of ischemic strokes, he received his Cadasil diagnosis. His mother also suffered from the same condition and was assisted by Frank throughout her long illness. Frank and his wife have managed to maintain autonomy and wellbeing despite the limited resources offered by their community. In 2021, they joined Novilunio's peer support groups in Padua and participated in a local support group for people with early-onset dementia. Recently, Francesco has discovered the power of poetry to express hardships and hopes after diagnosis. He is currently working on his first collection of 60 poems, which will be published later this year.

PHOEBE SHAW is Communities Programme Manager and coordinator of welcomes people in the local community, including refugees and asylum-seekers and recent immigrants to express their unique narratives through a diverse range of artistic methods. Artcore is a visual arts charity encompassing an art gallery, artistic studios, a shop, and a café. Artists have the opportunity to participate in local and international residencies. Artcore is a lively community hub dedicated to supporting and collaborating with local communities and offering tailor-made training workshops, catering to diverse groups, including senior citizens, recent immigrants facing language barriers, schoolchildren, youth, unemployed adults, individuals with physical disabilities, those with borderline mental health issues, and members of BME and LGBTQI+ communities.

DR FRANCISCA STANGEL is PROJEKT ENCOUNTER's drama workshop director. Originally from Sweden, she is a clown, theatre maker and applied theatre practitioner. Her passion for working with young people and marginalised communities led Francisca to co-create performances with refugees, asylum seekers and migrants, as well as with organisations such as Clowns Without Borders UK. She is a company director of award-winning Acá Theatre who make witty and slapstick-tastic performances for young people, and works as a freelance performer, director, producer and facilitator. With a PhD in Elizabethan drama, Francisca is a guest lecturer at the University of Kent, and frequently facilitates workshops in clowning, ensemble, LAMDA, classical theatre and physical theatre.

ELOISA STELLA is an applied anthropologist, a social communication specialist, and the current President of Novilunio. A graduate of University of Toronto, over the past years she has assisted a variety of for-profit and non-profit organizations in Italy and Canada in developing and promoting community building projects, engaging stakeholders, and establishing liaisons with private and institutional partners. She also assists in the development of innovative community-based public health and social care services aimed at improving the wellbeing and dignity of people with or at risk of dementia.

KATE SWAFFER is researcher and published author and poet, with a MSc in Dementia, Bachelor of Psychology, Bachelor of Arts, GradDip in grief counselling, and retired nurse. She is a global campaigner for the human rights and disability rights of older people and people with dementia, having won numerous awards, including the 2017 Australian Of The Year in SA. Kate has played a vital role as a catalyst for change in dementia globally, and co-founded the Dementia Alliance International, a global group for people with dementia. She lives with young onset dementia and writes about her experiences on her website.

ALEXANDRA TAN, Social Prescribing Student Champion, Social Media Lead, is a fifth-year medical student at Imperial College London. Alexandra took a social prescribing optional module as part of her primary care block in her 3rd year of medical school. One critical issue that they delved into was the alarming problem of overprescribing. The statistics they encountered left her in disbelief. *Over 10% of medications prescribed in primary care are unnecessary, resulting in an annual waste of approximately 2 billion pounds on 'unnecessary' medications*. Learning this led Alexandra to reflect on her medical education. How had such a critical problem been overlooked? Why was it only in her third year that she had been exposed to this aspect of medical practice? It became evident to her that there was a pressing need to address the gaps in their training to ensure that future healthcare professionals are equipped to combat overprescribing effectively. Alexandra's aim is to empower fellow students and healthcare professionals to embrace social prescribing. There has been solid evidence of its effectiveness, and by spreading this knowledge and encouraging its implementation, we can make a tangible difference in the lives of patients and the wider NHS.

TIZIANO TRACANZAN is an advocate with dementia who received a diagnosis of early-onset Alzheimer's two years ago, at the age of 62. Born and raised in Grantorto, a small village near Padua, Tiziano worked for several years as a Sales Account Manager for Italian, Swiss, and American companies. He has travelled extensively both in Italy and in other parts of the world, for work or pleasure, with his Harley Davidson bike. Tiziano was the primary caregiver for his mother, who died of Alzheimer's over 30 years ago. In 2022, he joined Novilunio's local peer support group for people living with dementia. Last year he also joined as a member and co-facilitator of a support group for people with aphasia. He also contributed to the design of the cultural activities programme for families associated with Novilunio.

RACHEL TRIBE is Professor of Applied Psychology at the University of East London. In 2014 she was awarded the British Psychological Society Award for Challenging Social Inequalities in Psychology. Rachel is a Fellow of the British Psychological Society and an HCPC registered psychologist. She has over 30 years' experience of developing clinical services and conducting research in the UK and abroad. She is active in national and international consultancy and training work. She has experience of working in the private, public, charity and academic sectors. She has worked clinically with a range of diverse communities. She has published widely on migration and mental health, refugees and asylum seekers, community psychology, critical psychology, social justice, professional and ethical practice, ageing and trauma. Currently a member of the BPS Presidential Task Force on Refugees and Asylum Seekers, Rachel was a member of the Royal College of Psychiatrists' expert panel on Improving Services for Refugees and Asylum-Seekers and the World Psychiatric Association's Task Force on Migration and Mental Health. She co-wrote the BPS guidelines with Dr Kate Thompson on Working with Interpreters in Health Settings. Professor Tribe also co-edited a book on Working with Interpreters in Mental Health with Dr Hitesh Raval, re-issued in 2014. In 2011 with Dr Pauline Lane she produced a DVD and guidance notes on Working with Interpreters in Mental Health for the Department of Health. Rachel is Chair of the International Mental Health Charity Careif.

DR ANGELIKI VARAKIS-MARTIN is a Lecturer at the School of Arts (drama and theatre) at the University of Kent. She holds an MA and PhD from Royal Holloway, University of London, UK. Her main interests and publications are in Greek theatre and masked performance. She has published numerous papers on the Greek mask and is currently working alongside colleagues and participants in PROJEKT ENCOUNTER to explore how masks enhance physical expression and creativity in applied drama workshops and/or a performance featuring migrants and vulnerable participants whose first language is not English. In her role as employability lead for the division of Arts and Humanities, she is working to develop and/or maintain strong links with arts organisations, such as PROJEKT EUROPA in order to support their impactful projects. Through our collaboration with PROJEKT ENCOUNTER and their work with refugees the university aims to link its employability initiatives to its civic mission and to create a model of community work where Arts education, academic research and student experience informed by external engagement - such as volunteering, and work experience - helps build bridges with external partners and vulnerable communities that can benefit from our support.