



See Me in Health and Social Care – Lived Experience Gathering **Event Report**

See Me has known for some time that health and social care settings are often places where mental health stigma and discrimination occurs. However it is a complex issue within a huge system that is increasingly under pressure itself. Never the less tackling stigma and discrimination in health and social care is a priority for us. This Gathering was an important step and has given us more evidence, experiences and, I hope, people who want to work constructively with us to influence change. It is a precious gift to share our life experiences with each other and many people did at our event. I'm grateful to them for their time and support for See Me.

– Calum Irving, Director, See Me

In October 2017, See Me held a gathering to hear about people's experiences of using health and social care services when they are struggling with their mental health. The event was important to make sure that the programme is working to make changes in the areas that need it most. We had 23 people in attendance, 4 of whom were See Me volunteers.

The event was chaired by Toni Groundwater, Social Movement Manager, who ensured that we managed to cover a content filled day and everyone was able to participate.

Benjamin McElwee, Health and Social Care Policy and Practice Officer, presented the latest thinking on the See Me approach within health and social care. This is:

- Taking a **public mental health approach** (targeting the circumstances that may lead to mental health issues arising e.g. limitations in opportunity in education, employment, access to preventative health and social care, etc.)
- Pushing for **mental health inclusion** (ensuring that reasonable adjustments are made for people with mental health issues and that their needs are included, listened to, understood and acted upon within the health and social care system and the systems that surround it.)
- But **to enable this we need anti-stigma and discrimination work across settings** (targeted work to remove stigma and discrimination at all levels – structural, institutional, cultural and personal)

Lived Experience

Gemma Welsh, a See Me volunteer, who also participated in the Health and Social Care Senior Leaders Seminar, shared bits of her personal story, alongside some of the solutions she saw.



"My GP asked me to come back every two weeks to check in. He thought it would be helpful, so that I didn't go so long without seeing anyone, while I waited for counselling.

I came away thinking 'wow, he actually cares'.

Previously I thought it was a good experience if a GP wasn't judgemental, but now I have seen how good it can be if you're treated with compassion."

Wendy Halliday, Assistant Director of Programmes, explained the importance of social movements, how embedding lived experience is crucial to ensure See Me is different in a deliberate way, and about the range of ways which people can get involved – from ad hoc investments of time to more concentrated project-focused work that comes about as a result of intensive training through the Community Champions programme.

Wendy also outlined the current and future opportunities that exist for people to use their experiences, both good and bad, to help develop the health and social care workstream. These include:

- Engaging in policy consultations;
- Social contact activities within health and social care settings;
- Involvement in [Distress Brief Intervention](#) implementation and evaluation;
- Developing public messages for a health and social care campaign;
- Developing content for the See Me website (e.g. blogs, case studies, videos);
- Sharing their stories on Care Opinion.

During the day there were 3 discussion sessions, allowing for an opportunity to truly learn from people's experience and expertise.



Discussion Session 1: What Works (and doesn't) within health and social care settings

The first discussion session revolved around some of the different settings within health and social care that people with experience of mental health issues may encounter.

Community Assets

The assets that exist in a community comprise not just the formal community organisations or voluntary groups but also all the informal networks and ways that people come together: football teams, pub quiz teams, gardening groups, walking groups, workplaces and so on.

It was felt that **community assets provide real benefits by enabling people to self manage their conditions, connect to their communities, and engender peer support.** However the name Community Assets was highlighted as potentially confusing.

Groups that enable people to gain skills, particularly if these are accredited, or can lead to a future product that may generate income were particularly welcomed (e.g. arts and crafts groups). However, people find it too hard to keep up with what is available and felt that **staff within health and social care often don't know either and therefore don't appropriately signpost.**

A key feature of assets was that their criteria tend to be less restrictive, and thus they are generally more accessible. However, whilst resources that aren't specifically for people with mental health issues are *generally* more inclusive and less othering, staff may not have the skills to appropriately deal with any issues that arise in terms of group dynamics, creating a safe space, or properly understand how mental health issues impact on people.

"We need to know the options - what is out there? Sometimes GPs don't know."

"It took 18 years to be told about Carers' Link by the social work department."

"Community options are the everyday means by which everyone manages their own mental wellbeing."





- There may be a role for Third Sector Interfaces to gather this information and share and promote it locally, with not only communities but also staff working within the health and social care system.
- Digital resources that seek to asset map communities like [A Local Information System for Scotland \(ALISS\)](#) should be continually improved and shared with the public and used by staff.

GPs and Primary Care

There was a real range of experiences for people within this setting, with some feeling like **GPs were not sufficiently trained in mental health** or could be **dismissive of people's experiences**. Other people however said it was down to the individual GP, and provided you were **able to find one that listened, cared**, and was able to provide continuity of care, then the experience could be very positive. People wanted someone who took their opinion seriously and valued their insight into their symptoms and/or condition, whilst also appropriately looking after their physical health.

It was felt that GPs should be more aware of and share all the treatment options (i.e. more than simply medication), and empowering people to know their rights and know what they can ask for (even simple things such as a double appointment). Tackling some of the access issues (post-referral from GP) was seen as particularly important.

"You're only taken seriously if you're suicidal. If you're thinking of throwing yourself off a bridge you can get help."

"There needs to be more information easily available to people to help them decide what they want, so when GP asks, "What help do you want?", you can say."

"GP asked about life and what life was like when doing well - to look at what could be done to help."

"My GP arranged regular check-ins whilst I waited for psychiatry."





- As Realistic Medicine shifts from policy aspiration to implementation, it's important that the ethos of movements like "What Matters to You?" day and personal outcomes approaches is embedded to delivery truly person-centred care.
- With the imminent roll out of link workers in GP practices across Scotland, we hope to see an increase in social prescribing. To do this in the most efficient and sustainable way possible will involve increasing all practice staff's awareness of community assets and their capacity and confidence in supported signposting.
- As Primary Care transformation gets underway, it's essential not only that access to mental health care services is increased, but also that there is a more inclusive approach (e.g. increased mental health literacy amongst all staff) , and different and innovative ways of supporting people with mental health conditions are delivered (e.g. Income Maximisation Workers embedded within GP practices).

Social Care and Social Settings

People **felt that within social care they may be subject to discrimination**, and there was concern about losing access to children if diagnosed with a mental health condition and involving social care. There is also a lack of parity of esteem as for one person their mental health support stops on bank holidays – they felt this wouldn't be the case with physical social care.

People **wanted services to better communicate with each other**, not only between health and social care, but also with the police, housing associations, etc. They also wanted **greater clarity from health and social care on where one service ends and the other begins**, however, felt it was inappropriate for example social work to stop when care starts.

"That was my first thought when diagnosed, that someone would take my kids away."

"My mental health support stops on bank holidays. Would physical support?"

"There is a need to empower people to know/speak about their rights."





- See Me is currently piloting a Community Conversations toolkit to ensure people feel more confident about their rights, and how to claim them. See Me will be tailoring the content based on the feedback received once the evaluation is complete, and then training volunteers in delivering the toolkit within their communities as part of our ongoing commitment to [Rights for Life](#).
- See Me will work to support job groups to integrate a mental health inclusion agenda within their clinical practice, e.g. during Stigma Free September at Hairmyres hospital, See Me, Lanarkshire Links and NHS Lanarkshire delivered workshops with nurses, dieticians, psychiatrists, and newly qualified doctors.
- With health and social care integration underway, it's imperative that – [as we have argued before](#) – the principles of the legislation are delivered upon, including that it is seamless from the point of view of the person using the service and that people's particular needs are taken into account.

Hospitals and A & E

Unfortunately people's experiences of these settings when presenting with a mental health issue was **generally not positive** – common complaints included, overt focus on physical health, lack of ability to deal with mental health problems (from not understanding issues right through to lack of appropriate treatment), excessive waits, and people wanting to avoid ever presenting in a hospital setting again due to the strength of their negative experiences.

Lanarkshire Association for Mental Health (LAMH) peer support workers in A & E were seen as a positive service. It was thought that a **more appropriate setting for people experiencing mental health problems would be beneficial**, either within A & E (but less chaotic and quieter) or possibly something that builds upon the example of the Safe Havens in Surrey which is open out of hours, available to people in distress, and utilises a much less clinical approach despite being staffed by clinicians.

It was felt that **services linking up better could lead to more appropriate responses**, particularly if the police were able to ensure their policies and procedures were suitable for each individual case presenting.

Anticipatory care, personalisation, and understanding of people's preferred coping strategies were all seen as routes to delivering more effective and safer care.



“Coming home to family is better than returning to an empty home.”

“Upon going through psychosis, a man was picked up by the police and taken to nearest hospital. Police phoned patient’s mother at 3am asking to pick him up. She was woken up, cannot drive, and therefore could not [pick him up]. Mother phoned son’s usual centre, who phoned hospital to arrange for son to be transferred and get a bed. But this did not happen. Stranger assessed the son as fit to leave and police released son.”

“Staff would prioritise other patients with physical health issues, as their attitude was “mental health problems can wait” – but they’ve actually been experiencing these problems for a long time!”

“[A person] had to wait in an ambulance for hours at Queen Elizabeth due to over-burden. Mother came and they released patient to her without patient seeing staff. There was a referral to social services but social services did not know about this.”

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- See Me is working alongside those involved in Distress Brief Intervention at the national and local levels, to ensure that the pilot truly delivers an alternative way of working within crisis settings, so that staff and people accessing support and services experience compassion and are empowered, and other factors are considered (e.g. physical environment, staff wellbeing).
- See Me will continue to support specific job groups to mainstream mental health inclusion, e.g. participative workshops on stigma and discrimination have been delivered to Scottish Wider Access Programme (Nursing) students at Kelvin College, and to various job groups at Hairmyres Hospital.
- See Me and the Mental Health Foundation are currently working on a project – as part of the [Scottish Mental Health Arts festival](#) – combining the arts with health and social care stories to find out more about the experiences of people, including staff.



Mental Health Services

People complained that not enough time was spent with them by services. **Services turning everything into a symptom was seen as an issue.** People also mentioned feeling disempowered if identical complaints were addressed when raised by advocacy but not by them.

Clinicians not properly considering the interplay between physical and mental health was highlighted. People also raised the point of how hope-defeating it was to establish that there weren't appropriate support or services available to them whenever they did seek help.

"My university counselling service told me I was fine and there was nothing they could do because I did not pose a threat to myself or others. Then I went on to have a mental breakdown and now a year later I am finally being cared for an understood."

I remember being told by a Community Psychiatric Nurse (CPN), "We aren't really here to look after you; we're just here to get you through the queue."

"Whilst living okay with my underlying mental health problem it was a comfort to believe if there was a crisis, help would be there. Now I've had a crisis and know there isn't; therefore, there is no hope.

- 'If you're calling us you have insight so don't need help.'

"Symptoms being turned into diagnoses means assumptions that you must have this symptom/behaviour/risk - 'my cat has four legs, this dog has four legs, therefore my dog is a cat' - I am not a diagnosis."

"Waiting lists are too long. This harms recovery if you do not have support from family and so on. When you get your appointment things have changed so it is too late."

"My CPN wouldn't listen to me, my opinion on my abilities or how I hoped to move on with my life. Just because I have mental health issues doesn't mean I want to sit inside the house staring out the window."



- See Me will be working with Health and Social Care Partnerships and other partners like Healthcare Improvement Scotland to ensure that service transformation leads to improved outcomes and experiences for people accessing services.
- See Me is working with the Scottish Government and others on some of the key actions within the Mental Health Strategy 2017-2027, as well as considering what the health and social care landscape should look like at the mid-way point of the strategy for people with mental health issues.
- See Me is working with the Scottish Human Rights Commission, Support in Mind, Bipolar Scotland and the Mental Welfare Commission to take forward the Rights for Life agenda by trialling improvement in three local health and social care partnership areas / NHS Boards





Discussion Session 2: Digital Health and Social Care Strategy 2017-22

In order to highlight to people what we mean by opportunities to get involved in policy consultations, we thought it would be beneficial to give people an example.

Therefore for the second discussion of the day we had input from Mark Simpson, Communications and Engagement Manager within the Digital Health and Care Division at Scottish Government. He presented briefly on the [Digital Health and Social Care Strategy 2017-22](#), before opening up table discussions with 2 main questions about the opportunities and barriers to the uptake of digital health and social care.

Whilst some people may have reservations about discussing digital, or felt that it didn't particularly apply to them or the cause of ending stigma and discrimination, actually it was imperative that the voices of those who said they wouldn't engage with digital services were in the room and were heard to try and avoid future discrimination.

Below are some of the most common themes that arose from the questions:

What do you see as the opportunities for digital?

- Access to information (about diagnoses/conditions, symptoms, treatments, services)
- Self monitoring and self diagnosis
- Multi-purpose apps e.g. Symptom tracking or medication reminders
- Self management
- Peer support
- Appointment setting

"The internet can be really useful for letting you know what's out there and what services exist."

"It's good to be able to book GP appointments online and choose your GP, without having to talk about problems."

"Digital brings anonymity and therefore reduces stigma."

"Information on the internet can help people understand diagnoses."

"People that aren't that confident on the phone could use messaging services instead."



What do you see as the barriers to digital?

- Uncertainty/discomfort about data-sharing, technology, tracking across websites, cyber-security, etc.
- Access to too much, incorrect, or insufficiently moderated information
- Access barriers (e.g. digital literacy, disposable income, compatibility with accessibility software (e.g. for dyslexia or sensory impairments))
- Might lead to more isolation
- Risks of human error and bias permeating through technology

"How can you trust an app? You can build trust with a doctor."

"I just don't think we should be rushing to go down the digital route for everything. We are already losing too much human/social contact as it is due to digital things."

"Big companies will go there [i.e. into digital health technology] for the money."

"Can't allow digital technology to replace human contact."

"Drop down boxes are impersonal."

"Can it create isolation? We don't even speak to people in shops..."

"Not everyone has access to computers so there must be local resources like libraries available... but a lot of them have closed so maybe health services should provide access"

[**A more comprehensive note of this session is available here.**](#)



Ideas and Networking

We rounded out the day by allowing people to informally share opportunities with each other that they saw for tackling stigma and discrimination locally, regionally, and nationally. There were refreshments and delegates were able to make use of the room for as long as they wanted, and we were pleased to see some folk take the opportunity to continue their conversations, whilst others introduced themselves to staff members and spoke of their interest in staying involved in the work of See Me.

Key consultations/policy developments we seek to influence in 2017/18:

- Realistic Medicine
- Nursing 2030 Vision and Action Plan
- Suicide Prevention Action Plan
- Community Empowerment Act
- Our Voice

Next Steps

All of the information that we gathered at the event will be used to further inform our approach and our engagement with others on health and social care related issues – for example, we have already had opportunity to use some of the quotes and experiences in a presentation to the NHS Greater Glasgow and Clyde North West Mental Health Hub. The experiences that people shared with us were invaluable in helping us further understand some of the challenges within the different health and social care settings, and confirmed to us that we are on the right track with the ones that we have identified as problematic and often unsuited to the needs of people with mental health issues.

We collated all the table discussions on the Digital Health and Social Care Strategy 2017-22 and fed them back to the Scottish Government. We will further use this to advocate for people with mental health issues as the Strategy is developed to ensure that it aligns with their hopes and allays their fears.

Feedback from attendees indicated that they found it particularly valuable to be able to share experiences with people of all ages, and to speak to other likeminded people who they shared common experiences with.

We also look forward to recruiting people to become Community Champions with a specific interest and focus on improving health and social care.