

# WeCAN

## Project Report and Youth Panel Model



**We can... with you!**

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Mental Health  
Foundation  
Scotland

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# Introduction



## Background

In January 2019 the Mental Health Foundation Scotland were awarded funding by The ALLIANCE following the successful UCAN project (2016-2018) which explored mental health and wellbeing self-management techniques for those with long-term medical conditions (LTMC). The culmination of the UCAN project was the development of the StressLESS Facilitator Pack which is a folder of activities and resources for facilitators that are inclusive of those with LTMC but can be used flexibly in work with young people across a variety of contexts.

With The ALLIANCE funding, we embarked upon a youth-led project called We CAN. The project took the form of a Youth Panel, focused around exploring how health and social care services in Greater Glasgow and Clyde meet the needs of young people with LTMCs.

## The Problem

Studies have shown that around 80% of GP appointments are filled by patients with long term health conditions, and a significant proportion of those patients are disclosing challenges with their mental health and wellbeing.

A King's Fund study in 2012 found that 'between 12 per cent and 18 per cent of all NHS expenditure on long-term conditions is linked to poor mental health and wellbeing'<sup>1</sup>.

Not only does this indicate a significant negative impact on peoples' livelihoods, but health and social care services are facing difficulties in adapting services in the right way to meet their needs. Therefore, uncovering first-hand experiences from those using these services will provide crucial insight into what and how change should be made.

## Youth Panel Aims

- to create a campaign raising awareness around the mental health of young people with LTMCs
- to promote the youth voice, empowerment and capacity building throughout all activities
- to influence policy and practice within services that support young people with LTMCs
- to create space for the Youth Panel members to develop a deeper understanding of themselves and their conditions and to build skills in speaking confidently when sharing their experiences with others

1. 'Long-term conditions and mental health: The cost of co-morbidities', Chris Naylor, Michael Parsonage et al. Feb 2012, Kings Fund, Centre for Mental Health.

# Our Youth Panel Model



## Building the Youth Panel

The project was coordinated and facilitated by the Youth Participation Team within the Mental Health Foundation Scotland. Through third sector and education contacts as well as social media advertising, we recruited 10 Youth Panel members aged 13 to 25, all with long term mental or physical health conditions and a passion for improving the lives and experiences of others facing similar experiences.

## Youth Panel Sessions

Once established, the Youth Panel met for a total of seven months – fortnightly for five months and weekly for an additional two months. We believe that the session structure and model that we used could be applied and adopted with young people in a range of different contexts and towards different goals. Facilitated by the Youth Participation Team, sessions consisted of:

Developing social connections and trust between Youth Panel members and facilitators

Identifying issues in order to build a communal campaign voice

Establishing an understanding of activism and campaigning

Discussing solutions for tackling the issues that were raised

Connecting the Youth Panel to the wider work of the organisation

Engaging the Youth Panel with external stakeholders and experts in their area of interest

Building confidence around public speaking and constructing their own stories

Exploring storytelling and other creative methods of raising awareness

Planning and executing an innovative campaign and interactive events

Evaluating the project's impact and success

Additionally, we organised some more informal meet ups such as a visit to the Edinburgh Fringe Festival to see a show related to LTMCs and a pizza night at the end of the project to celebrate the hard work and success of everyone involved. The three key activities of the Youth Panel are explained in more detail on the next page – our Day in the Life Campaign, Arts & Craftivism Event and We CAN Conference.

# Youth Panel Key Activities



## Day in the Life Campaign

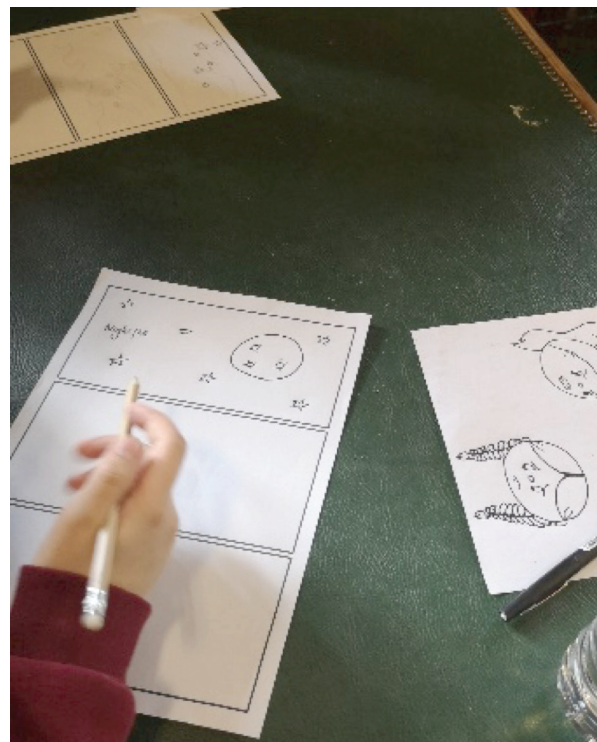
It was established early on that Youth Panel members were passionate about raising awareness around the side-effects and daily impact of living with a LTMC. The Day in the Life campaign was created in response to this, with a focus on exploring and uncovering the everyday experiences of young people living with LTMCs. There were a number of core strands to this campaign.



## MAIK Scotland

MAIK Scotland are an innovative engineering company who connect with individuals and communities to explore how they can share a story through building products.

We held a prototyping session with MAIK where we discussed some of the challenges the Youth Panel members face on a daily basis in relation to their conditions and how these could be exemplified by creating something that could be showcased and 'tried on' by someone. Although just an initial discussion, this innovative approach to raising awareness of lived experience motivated the Youth Panel members and fed into further discussions and approaches across the project.





## Arts & Craftivism Insight

Attendees of the Arts & Craftivism Event shared their experiences of different health and social care services as well as what they felt was important for the Youth Panel to focus on. They did this through interactive creative spaces and activities, all centered around the Day in the Life campaign theme.

## Art Competition

We launched an open art competition on our Day in the Life campaign theme at the Arts & Craftivism Event and displayed all entries at the We CAN Conference. We received a great response from young people across Scotland and delegates of the We CAN Conference voted on the winning piece at the event. We are exploring different ways to showcase these submissions to further explore and promote the campaign message.

## Arts & Craftivism Event

**Where:** Glasgow University Union

**When:** 15th June 2019

**Who:** The event was open to the public but specifically targeted at those living with LTMCs or those supporting someone who does and was attended by around 50 young people.

**What:** The Youth Panel organized an Arts & Craftivism Event to create an opportunity to engage other young people living with LTMCs to have their voices heard and represented, and to gather insight for our Day in the Life campaign. The day of arts and crafts

workshops, run by local artists, focused on how we can use creative methods to express ourselves and tell our story.

We had interactive spaces where young people could share their experiences and feelings creatively, and we later gathered and analyzed this all to inform our Day in the Life campaign.

## We CAN Conference

**Where:** The Lighthouse, Glasgow

**When:** 16th September 2019

**Who:** 42 delegates consisting of representatives from across:

- The Third Sector
- NHS
- Health Improvement Teams
- Education
- Academia
- Community Support
- Youth Work





**What:** A day of interactive sessions and engaging presentations. The Youth Panel had identified some core areas where they had experienced challenges within health and social care services and our speakers and sessions explored solutions and ways to address these issues to best support young people with LTMCs, for example:

- Transition from child to adult clinics
- Getting access to condition specific mental health support
- Understanding what your rights are in health care settings
- Connecting with community and third sector support

### Conference Structure

#### **MORNING – broad themes and experiences of the campaign and overall project:**

- Breakdown of the We CAN project
- An interactive introduction to the Spoon Theory
- Youth Panel sharing their own Day in the Life stories
- Interactive prototyping challenge (inspired by MAIK Scotland discussions)

#### **MID-MORNING – examples of best practice:**

- Audrey Kerr, Young Adult CNS Diabetes: 'Working together to support successful transitions from child to adult clinics'
- Sejal Patel, Principle Clinical Psychologist in Cystic Fibrosis: 'The need for specialist (but integrated) clinical support for those who long term health conditions'



- Izabela Mertowska-Shand, Development Officer for Versus Arthritis, and Jennifer Kane, ABI Coordinator, CBIT: 'Tapping into condition specific third sector expertise and resources'

#### **AFTERNOON – making changes in our own practice:**

- Rachael Hood, MHF: 'Long term condition inclusive resources and exploring the scope to support LTC including turning ideas to action and prototyping what change we can make'
- Elaine Lockhart, Consultant in Paediatric Liaison Psychiatry: 'Helping young people and practitioners understand the pathways to CAMHS and managing expectations'
- Dagmar Kerr, Area Coordinator Greater Glasgow and Clyde, Children's Health Scotland: 'The importance of designing your services to meet the rights of the child in health settings'
- Youth Panel member: 'My pathway to recovery and self-management through physical activity'



## Conference Feedback

We were encouraged by the evaluation feedback from delegates gathered via a post-event evaluation form.

Delegates were asked to reflect pre and post conference on their self-defined understanding of the needs of young people with long term medical conditions and we saw a significant increase from 56% to 81% in their level of understanding.

This was backed up by some key take away messages that delegates shared around the changes that they think should be made in their practice to make it more LTMC inclusive:

- “Get to know the young person and their individual needs; person first, patient second”
- “Environment is important, trust their abilities and provide better information at all ages and stages”
- “More awareness of other organisations, signpost when needed to help young people access positive mental health resources and support”





# Recommendations



## Policy and Practice

As a result of insight gathered through all of the We CAN project activities, we are calling for the following key **policy changes**:

- ① Specific LTMC trained CAMHS staff available for young people who want it
- ② Greater Glasgow Health Board embedding the NICE Transition guidelines into all of their services
- ③ An amplification and recognition of young peoples' voices in service design and delivery, through Youth Advisory Panels and Forums
- ④ Youth Workers to be part of the multi-disciplinary team in condition specific care teams

And the following key **practice changes**:

- ① Dedicated NHS staff in Accident and Emergency to support people who present with a mental health crisis – like suicidal thoughts or behaviours
- ② Clinical Psychologists within specific care teams and embedded within the multi-disciplinary teams.
- ③ Any engagement with young people guided by where they are, how they feel and what interests them.
- ④ The use of accessible and age appropriate language in discussions with children and young people



## Guiding Principles for Health and Social Care Practitioners and Professionals

Co-designed by young people, the Youth Panel and conference delegates, we have created the below guiding principles for Health and Social Care Practitioners and Professionals in how to best engage and support young people with LTMCs:

- 1** Listen to young people and take the lead from them, involving them in decisions impacting their care – ideally at service design level, but always in relation to their own direct care
- 2** Manage expectations and pathways to CAMHS services and be able to signpost to other organisations. Take the time to learn what is out there for the young people you work with across the third sector or in their communities.
- 3** Ask for access to LTMC training that is youth-led and designed
- 4** Understand that the young person exists in real life, not purely as a number on a patient chart, and learn about them, not just their condition
- 5** Understand the young person's wants and needs in relation to self-management and developing different coping mechanisms for their health and wellbeing
- 6** Be aware of the impact of trauma associated with a young person's condition
- 7** Be aware of the impact that the surroundings can have on the young person
- 8** Connect with other practitioners and professionals as is appropriate

# Activity Examples



## Dishing up a Message

*This is a nice ice breaker and fun way to introduce discussions about focusing your collective voice and message.*

Using paper plates, ask participants to draw up their core campaign messages, promoting and raising awareness of their cause.



## Musical Reflection

*Towards the end of your project, this activity provides a chance for participants to anonymously share their thoughts about how the project went.*

Give each participant a handful of post it notes. Title three flip charts 'Highs', 'Lows' and 'Next Steps'. Play some music and encourage participants to reflect on the highs and lows of the project and what they would like the next steps to be. Ask participants to write these down and stick them to the associated flip chart. Lead a discussion about what has come up through the reflection, what you can learn from it and what you can do next.

## Activism: What Comes to Mind?

*This is a useful activity to get participants thinking about methods of campaigning and start making concrete plans.*

Write up the word 'Activism' on a flip chart or board. Ask participants what words come to mind when they hear the word 'Activism'. Either writing these directly or using post-its, gather answers from participants without judgement or question.

It is likely that words like protest, riots and strikes will come up. Discuss with the group the pros and cons of some of the more extreme words that they have thought of, emphasizing that it is important in activism to ensure your message doesn't get lost in your actions. Lead a discussion about the different methods of campaigning that are realistic for the group, that everyone is comfortable with and will make the most impact.

As an example, research and discuss the work of someone like Sarah Corbett, award-winning campaigner and founder of the Craftivist Collective. Use other examples of campaigns and campaigners that best suit your cause and approach.





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