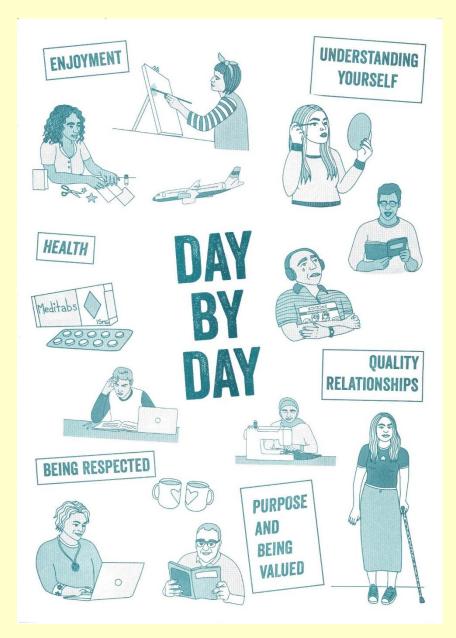


# Day By Day



# Priorities of people with long-term health conditions

August 2021

Unlimited Potential is a registered society under the Co-operative and Community Benefit Societies Act 2014 (Register number 30669 R at the Financial Conduct Authority).

Registered Office: Innovation Forum, 51 Frederick Road, Salford M6 6FP.



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# Summary

In spring 2021, Unlimited Potential spoke with 11 adults in Salford who had been on the 'shielding' list since March 2020, as a result of the COVID-19 situation. We spoke with people of different ages, genders, races, sexual orientations, backgrounds, faiths and reasons for 'shielding'.

We asked people about what they enjoyed doing and what they most valued in their lives. When we asked people how they managed their experience of having long-term health conditions, many people told us that they "take things day by day."

We wanted to collect people's stories and learn about the things that mattered most to them. People shared lots of individual and personal stories, and everyone's experience was unique. There were six themes that we heard most frequently:

- ★ Being respected people talked about the importance of being believed and understood by other people, as well as fair access. Some people spoke of not wanting other people to perceive them as 'ill', in order to avoid prejudice.
- ★ Health people talked about access to green spaces, exercise, being in spaces that felt clean and safe, day-to-day management of their health, and access to the health care system.
- ★ Understanding yourself people spoke about mental health training and therapy, as well as expressive creative outlets, such as writing poetry or expressing their personality in their style.
- ★ Purpose and being valued people talked about the importance of their work, learning new things, participating in social support groups or their faith community. They spoke as much about helping others as they did about being helped.
- **★ Quality relationships** people talked about their friendships, romantic relationships, pets and their family.
- **★ Enjoyment** people talked about things that were simply fun or distracting, such as television and movies, music, puzzles, shopping, travelling, art and crafts.

We want to use this learning to help us design, with people with long-term health conditions, projects that support them to have the best possible quality of life. It is hoped that the learning from the project will be:

- used to inform wider future developments in Salford, including through Public Health at Salford City Council and through the NHS in Salford
- shared with other parts of Greater Manchester

We want to thank all of the participants for taking part in this project, at what was an especially challenging time. We also thank <u>Jenny Gaskell</u> and <u>Anna Horton Cremin</u> for doing the project work.

# 1. Local focus - people 'shielding'

In response to a potential opportunity about tackling inequalities in August 2020, Salford approached Unlimited Potential. Based on locality conversations and challenges, and drawing on local intelligence, it was agreed in October 2020 to focus this proposal on people who were 'shielding', especially those who continue to rarely, if ever, leave their home.

People 'shielding' were those who were defined as 'clinically extremely vulnerable'. They include:

- solid organ transplant recipients
- people with specific cancers:
  - o people with cancer who are undergoing active chemotherapy
  - o people with lung cancer who are undergoing radical radiotherapy
  - people with cancers of the blood or bone marrow such as leukaemia, lymphoma or myeloma who are at any stage of treatment
  - people having immunotherapy or other continuing antibody treatments for cancer
  - people having other targeted cancer treatments that can affect the immune system, such as protein kinase inhibitors or PARP inhibitors
  - people who have had bone marrow or stem cell transplants in the last six months or who are still taking immunosuppression drugs
- people with severe respiratory conditions including all cystic fibrosis, severe asthma and severe chronic obstructive pulmonary disease (COPD)
- people with rare diseases that significantly increase the risk of infections (such as severe combined immunodeficiency (SCID) and homozygous sickle cell)
- people on immunosuppression therapies sufficient to significantly increase risk of infection
- women who are pregnant with significant heart disease, congenital or acquired
- other people who have also been classed as clinically extremely vulnerable, based on clinical judgement and an assessment of their needs; GPs and hospital clinicians have been provided with guidance to support these decisions

By the fact of 'shielding', these people had already been adversely affected by COVID-19 (coronavirus), and risked continuing to be so – as did their carers, many of whom had received less direct support and respite.

Although the Government formally 'paused' 'shielding' on 1 August, 2020, its guidance to clinically extremely vulnerable people (as at 18 October, 2020¹) still advised them:

- "Try to keep the number of social interactions that you have low."
- "Everyone is currently advised to work from home where possible."
- "Any carers or visitors who support you with your everyday needs can continue to visit."

With Greater Manchester subsequently placed in the highest tiers of COVID-19 restrictions during autumn, winter and spring, with associated 'lockdowns' imposed by central Government, for many people, this effectively meant 'shielding' for a year or more.

Further advice for 'clinically extremely vulnerable people' at local COVID alert level high ('tier 2'), included:

- "keep the number of different people you meet with low."
- "continue to go outside with your household and/or support bubble because of the benefits of exercise."
- "You should continue to work from home where possible."
- "avoid travel where possible except for going to work, school, or for essential shopping."
- "You should continue to receive care at home, either from professional social care and medical professionals, or from friends and family within your support bubble."

Further advice for 'clinically extremely vulnerable people' at local COVID alert level very high ('tier 3'), included:

- "you can only meet friends and family who are not in your household or support bubble in certain outdoor public spaces."
- "continue to go outside for exercise, but to avoid busy areas to minimise the chance of coming into close contact with others. Otherwise, we advise you to stay at home as much as possible."
- "Where at all possible you are strongly advised to work from home ... If you cannot work from home, and are concerned about going into work, you may want to speak to your employer about taking on an alternative role or change your working patterns temporarily."
- "stay at home as much as possible and avoid any travel into or out of a local COVID alert level: very high area."
- "You are advised to significantly reduce your shopping trips. Where
  possible, you should consider shopping online. ... You are advised to ask
  people in your household or support bubble to collect food and
  medicines for you."

<sup>&</sup>lt;sup>1</sup> <a href="https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19">https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19 (accessed 18 October, 2020)</a>

 "You should continue to receive care at home, either from professional social care and medical professionals, or from friends and family within your support bubble."

On 'shielding' specifically, the government advice was: "If formal shielding is introduced in your area, we will write to you setting out how you can access support if you need it in order to follow advice, for example, support to access food, medicines deliveries, advice or any additional wellbeing or practical support you may need."

There were 12,612 'shielding' people registered with GP practices in Salford. It is not known how many carers of these people that there are.

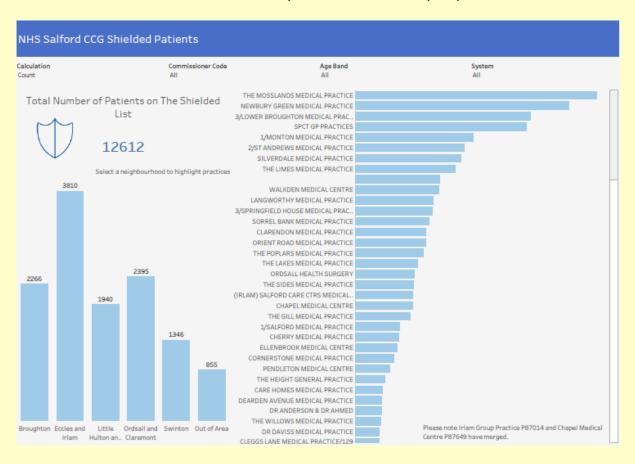


Figure 2: 'Shielding' people – overview (Salford Clinical Commissioning Group, August 2020)

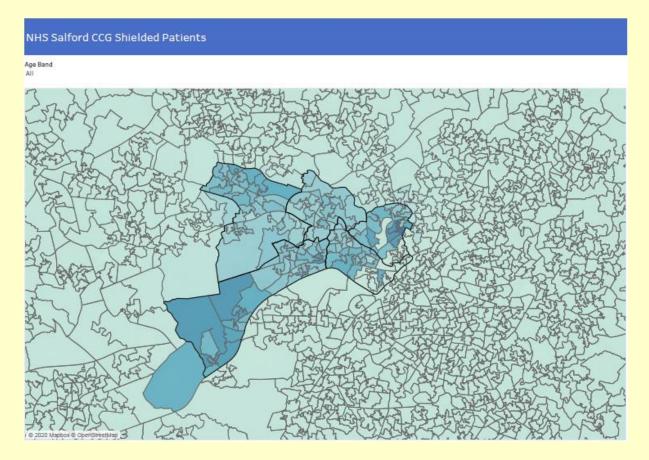


Figure 3: 'Shielding' people – map (Salford Clinical Commissioning Group, August 2020)

People 'shielding' disproportionately included people from these groups:

- lower socio-economic groups
- Black, Asian and minority ethnic communities
- disabled people
- people with long-term health conditions

While people 'shielding' were in all age groups, the highest numbers are in the age groups between 40 and 89 years old.

While much had been done since March 2020 to help and support 'shielding' people, there had been much less deep listening and understanding of their situations which, in many cases, existed in large part before COVID-19 (coronavirus). For many, the COVID-19 situation has simply exposed the issues that were already there but were often unknown to or ignored by others.

This was enhanced by fear generated by the COVID-19 situation. As one Community Connector from Wellbeing Matters in Salford puts it: "There is a genuine 'fear' for many who have 'shielded' of entering into the world again. After so many months of being in their 'safe' place, the thought of going out is unachievable ... From those who I have spoken with, whilst they know they can go out, they know the virus still exists and it hasn't

gone away, so they are asking the question of what has changed from their personal perspective, as their own health conditions remain the same or are worse due to being exacerbated by the imposed locked down for such a long period (inactivity/ lack of social contact/connections to outside world/ scaremongering etc.)."<sup>2</sup>

'Shielding' was again formally 'paused' by the Government from 1 April, 2021, but with little guidance<sup>3</sup> or significant support offered to the people affected.

There remains a risk that, as the rest of society 'moves on' and returns to 'normal' activities, the people 'shielding' and their carers will be 'left behind'. Given the uncertainty about the future impact of COVID-19, it is important that they are positively engaged in ways that suit them.

The crisis for many 'shielding' people and their carers presented by the COVID-19 (coronavirus) situation created challenges, but could also provide an opportunity to learn more how to collaborate with them to optimise their health and well-being.

# 2. Approach

The proposal was for Unlimited Potential to engage with people 'shielding' – especially those who may also experience poverty and/or inequality – to help them maintain, and hopefully improve, their health and well-being in ways that suit them, using the framework of the <u>five ways to well-being</u>. This would also include their carers, if necessary.

Importantly, we started from the premise that people 'shielding' and their carers are extremely valuable citizens with skills, knowledge, experience and other qualities to offer, rather than primarily seeing them in a deficit-based way as 'clinically extremely vulnerable'. Through this strengths-based approach, we sought to explore the potential to co-design and co-produce solutions with them.

We drew upon the seven stages of innovation, as described by Nesta:

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<sup>&</sup>lt;sup>2</sup> Email communication – 8 September, 2020.

<sup>&</sup>lt;sup>3</sup> <a href="https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19">https://www.gov.uk/government/publications/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-protecting-extremely-vulnerable-persons-from-covid-19/guidance-on-shielding-and-



Figure 4: Seven stages of innovation (Nesta)

This report covers phase 1 of the project, reflecting the first two stages of innovation.

# 1. Opportunities and challenges:

Drawing on the data about people 'shielding' supplied by <u>Salford Clinical</u> <u>Commissioning Group</u>, we first sought to approach and engage 6-10 'shielding' people.<sup>4</sup> Initially, we hoped to do this through GP practices, but the workload caused by the COVID-19 situation largely prevented this.

We therefore used community networks and contacts to engage a diversity of people in order to reflect the population of 'shielding' people, and also to generate high-quality thinking.

The purpose of this process was to gather people's stories and to explore them in detail to better understand:

- the problems, and their root causes
- people's hopes and fears
- the opportunities that a new change could bring about, and their enablers

<sup>&</sup>lt;sup>4</sup> Care will be taken to avoid any confusion with the <u>Wellbeing Matters</u> (social prescribing) programme in Salford, in which Unlimited Potential is a partner. The local Community Connector may, however, be able to help identify potential participants.

For this, it was essential to create positive relationships with people (as people) in which they felt safe, valued and wanted, which required time, respect and trust.

We therefore did not approach people with any 'agenda', whether health and social care or otherwise. The focus was on the agendas of people 'shielding', and drawing on them to inform subsequent stages.

# 2. Generating ideas

From the learning and reflection, including the <u>five ways to well-being</u> as a broad framework, we hoped to generate with people a range of ideas and possible solutions, with a view to creating something transformative. This might involve methods such as design thinking.

# 3. Learning and evaluation

We put a strong emphasis on learning from the insights of people 'shielding' about what is meaningful for them in maintaining and improving their health and well-being, while keeping them safe from COVID-19 (coronavirus). We sought to learn about the enablers and barriers to this.

Learning was gathered during the period of the project, with reflection done at regular intervals to inform subsequent actions. This has been compiled into this report.

# 4. Implementation

4.1 <u>Recruitment - outreach and artistic 'invitation' for participants</u> (March-April 2021)

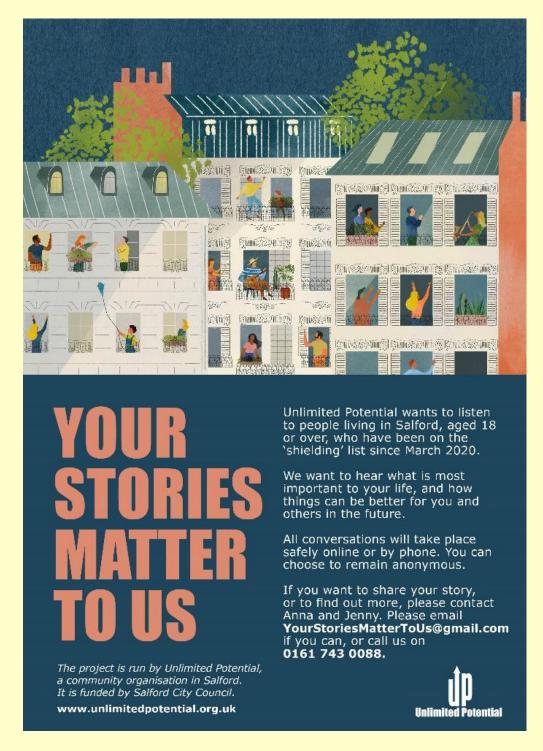
# Preparation:

A close contact who was 'shielding' was consulted on ideas and access considerations, in order to best collaborate with 'shielding' people.

Guidelines for the project and best practice for working with 'shielding' people were created, including drawing on advice from Arts at the Old Fire Station<sup>5</sup>.

An invitation for participants was created, which could be sent directly or through contacts and networks.

<sup>&</sup>lt;sup>5</sup> Arts at the Old Fire Station (2020), <u>A Guide to Using Storytelling to Evaluate Impact</u>, Oxford.



# Recruitment Process:

Initial contact was sought through GP practices, community networks and contacts, and VCSE organisations across Salford, with an emphasis on diversity.

As people came forward or were nominated, it was checked that they were on the official 'shielding' list and then interviews were arranged to suit individual circumstances, as well as avoiding any risk of COVID-19 (coronavirus) infection.

# Contact:

A new Gmail account was set up for the project - YourStoriesMatterToUs. This helped the team to keep all the data secure in one place, as well as Unlimited Potential holding the data in accordance with data protection legislation.

4.2 <u>Recording stories and transcription - trust building, confirmation and interviewing people</u> (April-June 2021)

To build trust and understanding, pre-conversations were held with potential participants to explain the project, the boundaries and safety - for example, that the participants would remain anonymous and approve any audio before it was used. A consent form was also used with each person (see appendix 1).

In-depth interviews of up to two hours were held with 11 people. These were semi-structured around these questions:

- What is your story?
- What is important to you? What matters to you?
- What would change your life for the better?
- What do enjoy doing the most?
- What are your strengths?

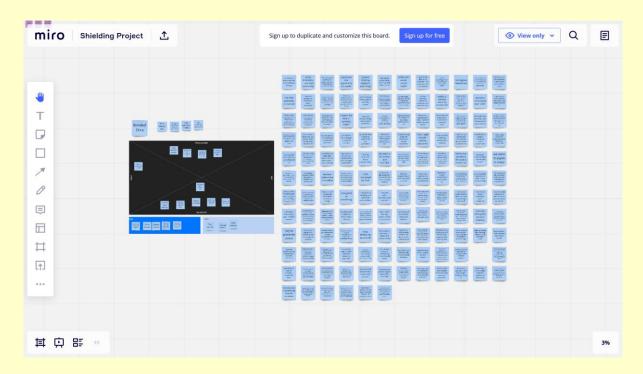
Where people had a computer and wifi at home, interviews were largely recorded using Zoom<sup>6</sup> (without the video function), but with alternatives to suit individual circumstances. Where people did not have a computer or wifi, the telephone conversation was recorded using a Dictaphone, with the person's verbal consent.

The automatic transcription app <u>Otter</u> was used to transcribe the interviews.

4.3 <u>Synthesizing the learning and evaluation - analysis of interviews and key themes</u> (June 2021)

Notes of key discussion topics were created from the audio pieces and transcripts, and then uploaded on to a <u>Miro</u> online collaborative whiteboard, using a 'virtual post-it note' for each insight/quote gathered from participants. An example from one participant looks like this:

<sup>&</sup>lt;sup>6</sup> Zencastr (studio-quality audio) was originally identified, but Zoom was used as it was realised that audio quality was less vital and Zoom was a more accessible and known forum for conversations for most people.



Affinity mapping was then used to pull out key themes and insights. Each insight was attributed to a theme, such as 'music', 'green spaces' or 'romantic relationships'. The affinity map helped the team to understand the common and prominent themes which recurred for multiple participants.

The <u>Miro</u> online collaborative whiteboard enabled the team to complete the affinity mapping process together, while working remotely. The affinity map, drawing out initial themes, looks like this:



An <u>empathy map</u> - a collaborative visualisation tool – was also created to really understand what people think, feel, do and say.

# 4.4 <u>Creation of artwork/gift and participant aftercare</u> (July 2021)

An artwork was created that responded to the stories that were collected. With people's strong emphasis on writing and recording their thoughts and experiences, this was created as a journal, featuring quotes from the interviews.

The designers of the journal were both people living with long-term health conditions themselves.

A copy of the journal was delivered to each of the participants as a gift, together with a 'thank you' letter from the Chief Executive of Unlimited Potential (see appendix 2).

Sufficient copies of the artwork were produced for distribution to key agencies and

professionals, in order to help create a 'heart based response', alongside the data in this written report.

# HOW TO TAKE THINGS DAY BY DAY. A DAY BY DAY JOURNAL FROM PEOPLE WHO LIVE WITH LONG-TERM HEALTH CONDITIONS

# 5. Participants

There was a diversity of people who participated in the project:

- there were two people in their 20s, two in their 40s, three in their 50s, one in their 60s and three who were 70 years or older
- there were seven women, three men, and one non-binary person
- there were nine white people, one black person and one person of Jewish heritage
- eight people were born in the UK, and three outside
- there were two people of faith one Christian and one Jewish
- most participants were heterosexual and cis gender, with one person identifying as asexual
- there was a wide range of educational experience from people who left the educational system early through to postgraduates

# 6. Themes – what matters to people?

From people's stories, we learned about the things that mattered most to them.

While everyone's story and experience was unique, there were six themes that we heard most frequently.

Three themes are similar to what would be expected from almost any group within the general population:

- ★ purpose and being valued
- ★ quality relationships
- ★ enjoyment

The other three themes are more particular to people with long-term health conditions:

- ★ being respected
- **★** health
- ★ understanding yourself

Each of the six themes is described below, together with illustrative quotes from participants.

★ Purpose and being valued – people talked about the importance of their work, learning new things, participating in social support groups or their faith community. They spoke as much about helping others as they did about being helped.

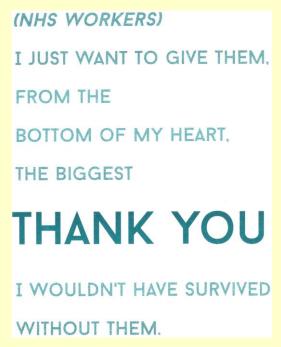




If I can help one person a day, I'm happy.

YOU'RE JOKING AREN'T YOU I SUPPORT EVERYONE ELSE. **★ Quality relationships** – people talked about their friendships, romantic relationships, pets and their family.





★ Enjoyment – people talked about things that were simply fun or distracting, such as television and movies, music, puzzles, shopping, travelling, art and crafts.



IF I'M IN A BAD MOOD, OR I WAKE UP UPSET, I GET UP AT 5, I GO TO THE KITCHEN, PUT A SAD SONG ON AND HAVE A GRY.

THEN

TWO HOURS LATER
I'M AS RIGHT

AS RAIN.

IT TRANSFORMED ME.

IF I'M GOING TO DIE,

I'M GOING TO DIE

BLOODY HAPPY.

I watch shoot 'em ups I want something to happen to the bad guy.

★ Being respected – people talked about the importance of being believed and understood by other people, as well as fair access. Some people spoke of not wanting other people to perceive them as 'ill', in order to avoid prejudice.





WHEN
PEOPLE
KNOW ABOUT
MY HEALTH,
THEY FEEL
SORRY FOR ME
AND
I HATE IT.

★ Health – people talked about access to green spaces, exercise, being in spaces that felt clean and safe, day-to-day management of their health, and access to the health care system.



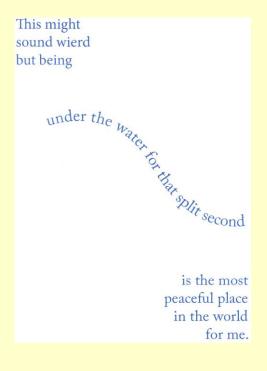
I've been to a gym
twice in my life

because

you get conscious

that

you can't do
what other
people are
doing.



So the barrier is just getting the right doctor.

You want — green spaces to go — stretching.

★ Understanding yourself – people spoke about mental health training and therapy, as well as expressive creative outlets, such as writing poetry or expressing their personality in their style.



I
don't
survive
on
hope,
I
survive
on
intrigue.



The psychologist in me helps me to **process.** 



# 7. Next steps

It is hoped that, from this initial project work and learning, we can make progress with phase 2 of the project, reflecting the third to the seventh stages of innovation:

# 3. Developing and testing

'How might we' questions can help to generate questions and to focus ideas, based on what people have said is most important. Ideas will be tested and strengthened through trial and error, either by simply trying them out in practice or possibly through more rigorous rapid prototyping. This will involve continual learning, adaptation and refinement from what does - and does not - work. This process might be with the people identified in stage 1 and/or with other 'shielding' people and their carers.

# 4. Making the case

Through further experimentation and trialling, the proof of the preferred concept will be developed, with evidence collected and shared honestly. Ideally, this will be done with a larger number and wider diversity of people 'shielding' and their carers.

# 5. Delivering and implementing

This is when the solution becomes everyday practice. It includes identifying what is working well, and what is not, as well as securing income streams that enable the long-term financial sustainability to carry the innovation forward.

# 6. Growing and spreading

In this stage, there is a range of strategies for growing and spreading an innovation. This might be organic and adaptive, through emulation and inspiration, or more structured, through organisational growth, or licensing and franchising.

# 7. Changing systems

Systemic innovation is where maximum social impact can be created. It usually involves changes in the public, private and/or VCSE sectors over long periods of time, and the interaction of many elements and new ways of thinking.

# **Appendices**

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# **Your Stories Matter To Us**

Thank you for signing up to be part of Your Stories Matter To Us.

Unlimited Potential are working with people across Salford who have been shielding during the pandemic, to understand the things which are important to them.

We will have conversations with you safely over the internet or over the phone. We encourage you to choose a time that suits your schedule and energy levels. We want to be flexible to your needs.

The recording of the interviews will be used to help Unlimited Potential develop new ideas for improving the lives of shielding people in Salford. These recordings will be held for up to 3 months after the duration of the project.

There will be a transcript of the interview that will be stored and anonymised, which means the words that are said will not be stored with your name attached.

The words that are shared may also inspire a visual artwork. This will all be anonymised and you can choose not to have your words shared with this part of the project.

You can withdraw your consent at any time during the project if you change your minds.

The project is run by Unlimited Potential and funded by Salford City Council. Unlimited Potential is a community benefit society, based in Salford, specialising in social innovation with local people and communities. <a href="www.unlimitedpotential.org.uk">www.unlimitedpotential.org.uk</a>

# Permissions:

I confirm that I wish to take part in a Your Stories Are Important To Us conversation.

I understand and acknowledge that through this process there will be documentation of myself through audio which will be stored for up to 3 months after the completion of the project.

I understand that I can withdraw or change my consent at any time.

Level of consent	Please tick
I give consent for Unlimited Potential to use this audio for research purposes and the quote and transcript to be used and shared with future commissioners, sponsors and funders which will be anonymised.	
I give consent for Unlimited Potential to use the transcript to inspire a visual artwork. This artwork will be shared with you before it is made public. The words used will be anonymised.	

Name	
Signature	
Date	

Unlimited Potential will never knowingly use audio that could be considered offensive or insulting and will not contribute audio to any third parties who it considers to be offensive or insulting, or use the materials to incite insulting debates or behaviour.



Innovation Forum, 51 Frederick Road, Salford M6 6FP phone: 0161 743 0088

web: www.unlimitedpotential.org.uk email: info@unlimitedpotential.org.uk

Date July 2021

Dear participant,

# Your stories matter to us

I don't know your name, as Anna and Jenny have made you anonymous to me and to everyone else who will read what you had to say, but I wanted to say a personal thank you for participating in our project.

When we were planning the project, we wanted to challenge the way in which people were being described with negative words such as 'vulnerable' and 'shielding'. We wanted to find out what matters to you and people like you, and you have generously helped us to do that by sharing your valuable wisdom and experience.

We hope that you like the gift that is enclosed with this letter. This is a thank you for your participation, which has been designed and created from the conversations that Anna and Jenny had with you and others.

We will be reporting back to the local council, the NHS and others on the key issues that you have raised, with a view to improving people's quality of life in Salford and beyond. As far as we can, we will also strive to reflect your voices in the media.

Thank you for your participation. We will do our best to make sure that it leads to positive changes on your priorities.

Yours sincerely,

Chris Dabbs (Mr.) Chief Executive







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