Gross National Care Index
AcrossRCA Project Proposal

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Gross National Care Index

This PDF document details our proposed Gross National Care Index and the process behind creating it.

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GNCI: Gross National Care Index

What is the GNCI?

The Gross National Care Index is a media, information and data collection campaign to gather data on the quality of health and social care in the United Kingdom for those providing care and receiving the care. To make a case to the UK Government that the wellbeing, happiness, and care felt by the population is as important a metric worthy of consideration and equal to measuring as a Nation's GDP and GNP.

We are hoping to demonstrate that it is essential, easy and feasible to collect information about how a population's FEELS and that it could hold a new imagination for other developing nations as an aim and hold value in a New type of World outside the exchange of goods that being of the mental and physical well being of a population that a Government should strive for for its population.

By gathering both qualitative and quantitative data on how individuals in the UK feel cared for through a series of questionnaires; to be used as part of our media campaign, we hope they will allow respondents to reflect on their own experience of care and recognise that there is opportunity for improvement and to also feel listened to and that they do matter - each and every one person.

Research Overview: How we Came to the GNCI

In early discussions there was a decision to survey professional care workers about their experience in the field. This led to the discussion of creating a survey and or video interview to sample as many professionals in the care industry or entering the industry to have a choice to participate in it.

There are a number of obstacles that emerged with this approach. We had to consider the implications of the actions – of both the interviewer and the interviewee. How could we create an approach that does not come out as a bias approach to a topic ; How do we create a safe environment for those who might have been traumatised by their experience (at one point there was a suggestion for a survey for those who have been cared for by professional carers) ; there were a number of ethical and safety against discrimination issues that came up.

After some time, we decided to clarify our approach and define what we think the

WICKED PROBLEM truly is which led us to consider Bhutan's GNH index.
To gather a nationwide census to the response of 'feeling cared for'. Bhutan is a tiny Independent Nation in the foothills of the Himalaya Mountains that created a Gross National Happiness index to measure the general well-being of its nation. They survey their population every 5 years and gather the results to produce a quantitative analysis as legitimate as any GNP or GDP of a nation.

Out of this we decided to Firstly Create the tiniest questionnaire for anyone who cares to participate to gather DATA to convince the public that there is a need to collect data for this and to hold the policy makers responsible for the quantitative index that can possibly be created from the data. Initially, there were discussions to create small qr codes highly spread in public spaces through visuals and attractive copyright to get some basic information to 'how cared for they feel' regardless if they were a carer, a professional carer, a patient or just a general member of the public.
This anonymous survey anyone on the street can take would then become data points to push for a much more specific survey of which a National Index can be created that would differ vastly from that of a National Health Index, which doesn't take into account any 'feelings' or how the system functions but more the data of those already in the system without any information about HOW the system works and for who.

Project Proposal

How Are you?
Really. How Are YOU?
This was how our shared Journey Started.

Conceptually Inspired by the work of The Kingdom of Bhutan's King who implemented the Gross National Happiness Index to measure the Wellbeing of his Subjects every 5 years in Bhutan in the same measure of consideration as his nation's Gross Domestic Product.

We have a very living and breathing brainstorm Padlet that continues to motivate and fuel us.

Everything from Graphic Designed posters, Stickers and other Communicative Media all with a singular QR code to various Media based Information and an Ethical and Accessible Survey.

This is wholly a voluntary survey in a 'yes and no' format.

Through this initial push through voluntarily accessible multi media information campaign available to anyone who wants to participate or are merely curious is to initiate a format that would mitigate any ethical risks that might come with information gathered for such a sensitive and personal topic.

Each of us have a designated role in this collaborative process. Our individual Passions aren't as much topic related as they are motivated by the segmented role each of us have taken in building this project TOGETHER. This allows us to wholly navigate each aspect of this project with very clear understandings of what is needed of us to make the project whole.

The Concept was initiated around the inspiration of policy makers from Bhutan. The Question was developed by a patient that has encountered various obstacles in her journey to find health and wellbeing. The Graphic Design Quality is both architecturally managed and designed by A communication and Functional Designer . We were very fortunate to have allocated our roles to our strengths.

We received feedback from our peers about possibly narrowing down our scope to a how a smaller, specific demographic feels about care within the UK. Although we acknowledge the difficulties that come with having such a wide target audience its important to us that we are not excluding anyone; as feelings of exclusion were incredibly prevalent in our initial research.

Literature Review

We want our project to have the potential to create change. Currently health and social care services in the UK are struggling to keep up with demand. Everyday there are new stories of the mistreatment of the public who cannot access the care they need, and the poor working conditions of those working within care. In order to narrow down where we can make an impact in the improvement of care we asked ourselves:

• What is already happening to change the current culture of care? •

What campaigns are running, and for who?

• What research has been done?

• Who controls quality of care?

• Where can we fit ourselves in?

This will help guide us on what to include in the questionnaire we put out as we can angle it to meet the topics that are most important to the public; as well as making sure we are demonstrating to the government why our proposed project is necessary.

Current UK Government Legislation on Health and Social Care and who enforces it

1. **The NHS constitution** is updated every 10 years, it very broadly outlines the values and goals of the NHS. Its latest iteration was published in 2015.

https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs constitution-for-england#principles-that-guide-the-nhs

2. The most recent legislation change is the **Health and Care Bill (2022**). It took ten years for this bill to be pushed through in order to update its predecessor, which was published in 2012. The Bill completely changes the structure of how health and social care structures are run. However, most independent advisory groups, advocates, activists, unions and charities completely opposed this bill as it was being debated. The information and research they presented to the government and parliament was ignored or warped. The current Conservative majority means the

government has the power to completely ignore experts and push through whatever changes they want.

The bill: https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted

3. The **Care Quality Commission (CQC)** is the independent regulator of health and adult social care in England. They enforce any of the health and social care legislation published by the government, including the Health and Care Bill.

The CQC has just finished five years of research on a new strategy for changing the world of health and social care:

'What we've learned from the past five years puts us in a better position for the future. Our new strategy combines this learning and experience and we've developed it with valuable contributions from the public, service providers and all our partners. It means our regulation will be more relevant to the way care is now delivered, more flexible to manage risk and uncertainty, and will enable us to respond in a quicker and more proportionate way as the health and care environment continues to evolve.'

More details of their work can be found on their website: https://www.cqc.org.uk/about us/our-strategy-plans/new-strategy-changing-world-health-social-care-cqcs strategy-2021

Responses to the Health and Care Bill:

1. The **BMA (British Medical Association)** is the biggest trade union and professional body for doctors and medical students in the UK. They opposed the bill the entire way through the legislative process due to how regressive they believed it to be. https://www.bma.org.uk/advice-and-support/nhs-delivery-and-workforce/integration/integrated-care-systems-icss

2. **Kings Fund** is an independent charitable organisation working to improve health and care in England, est. 1897. Their main issues with the bill was its refusal to help workforces and how it regresses social care. Both of these issues were due to the major funding cuts pushed through by the Treasury. They felt that the language in the bill gave more discretion to local leaders, which could allow positive change if communities worked together:

'It's an opportunity that leaves much discretion to local leaders rather than imposing a rigid one-size fits all that suits no-one. But this is just an opportunity – whether it is realised into actual benefits relies on the changes in practice and cultures that underpin a more collaborative, integrated system. That includes changes in national bodies such that they don't replace the permissiveness granted by parliament with their own rigid national blueprint. Most importantly it relies on people in systems and places continuing to learn how to work together, and that will need support, endurance and commitment long after the ink is dry on this Health and Care Act.'

Their whole response can be found here: https://www.kingsfund.org.uk/blog/2022/05/ health-and-care-act-2022-challenges-and-opportunities

3. **Patients4NHS** (patient run and funded resource for advices and action) damning response. They pulled apart every party of the bill and considered how it would negatively affect patients:

> 'The Act allows far more central control of the NHS, creating <u>138 new Ministerial powers.</u> Several of these will allow the Health Minister to use secondary legislation to rewrite law, meaning that, in some instances, legislation will be made without proper Parliamentary scrutiny or debate.'

Their analysis was terrifying but enlightening. It really shows how poorly the government values health and social care services, and by extension how little they care for those who use them and work within them.
https://www.patients4nhs.org.uk/the-health-and-care-bill/

The main question we had after looking into the response to the bill was: **is pushing for legislation change a worthwhile venture in the current climate, when the government is not listening to advice?** Health and social care is politicised, whether we like it or not, if our ideas don't side with their priorities it is unlikely we will have any success in pushing for changes of legislation. We need to think more radically on how to approach this. Maybe what is need is an entirely different way of showing lawmakers how inadequate their current policies are.

What is already happening to try and change the current culture of care?
What should be done? Why isn't it happening? What work is being done?

1. The **Health Foundation** raises the point that not many know what is happening to health and social care unless they are involved with the system. They suggest that if there was more understanding of what was happening then less people would be willing to accept current systems.

They have also performed a research survey (2022), involving over 7,500 people in the UK, to better understand how people think about health. They asked what the public think makes 'a healthy place':

'This shows a clear mismatch between the essential role local authorities play in our health, and the relatively low awareness among the public of what is being done in their local area to improve health. So how can we engage people more effectively in the conversation about what is needed – and what is being done – to improve health?'

https://www.health.org.uk/publications/long-reads/what-should-be-done-to-fix-the-crisis-in-social-care
https://www.health.org.uk/news-and-comment/blogs/what-makes-a-healthy-place-some-answers-from-the-public

2. Changing how we think about disability through the **Social Model of Disability**. More, and more, advocacy groups have been adopting the Social Model of Disability in their approach to health and social care activism. Disabled people make up ¼ of the world's population. How they want to be cared for is a very important

factor of considering a caring society. This models suggest the most disabling thing in society is how disabled people are treated rather than what's "wrong" with them. It is a model that values accessibility, and recognises that negative attitudes based on prejudice or stereotype stop disabled people from having equal opportunities.

https://www.scope.org.uk/about-us/social-model-of-disability/

3. Online organising, such as **Scope's Online forum**:

Online communities are an amazing space for change, especially for disabled people who may not be able to organise or meet in person. It shows how communities can share knowledge and help people to advocate for themselves, also a good way to find understanding that the general public cannot provide. Scope is a charity that focuses on supporting disabled people in the current climate, as well pushing for positive change. Their online forum us a great example of getting disabled voice's heard.
https://forum.scope.org.uk/categories/disabled-people?
_ga=2.35663719.674667243.1666112133-640769823.1666112133

4. Ethical Caring design is an alternative option to legislation change that could improve how well people feel cared for. **Cennydd Bowles 'The Ethical Designer'** talks about the value of partnership over empathy. He believes empathy is a necessity, but it's not as needed as representation and partnership with minorities (disability/race/lgbtq+/etc.). He also champions the voices of others designers who champion inclusion:

''We can't pretend that our empathy is as good as having lived those experiences ourselves. Empathy is not a stand-in for representation.'- Eva PenzeyMoog in Design for Safety.

https://cennydd.com/writing/book-review-design-for-safety

5. **Campaigns pushing for the inclusion of disabled people in Health and Social Care activism, advocacy and legislation change** are becoming more common, and are certainly more needed. Disabled people receive the most care, but are frequently ignored. We have to be sure to include those who are cared for in our vision for a caring society. Their input is essential before making any major decisions. Some example I found of this are:

1. **Why You Need To Start Including Disabled People In Your Health Care Activism** is an article from a USA point of view, but is still a powerful and persuasive read: https://medium.com/the-establishment/why-you-need-to-start-including-disabled-people-in-your-health-care-activism-77e7c0b3a125

2. '**Lucien Engelen: Patients not included'** is an article published in the BMJ (British Medical Journal) by an influential doctor of the BMA. It is a good example of the personal forms of activism that doctors and researchers can perform.

"I will 'NO-SHOW' at healthcare conferences that do not add patients TO or IN their programme or invite them to be IN the audience. Also I will no longer give lectures/keynotes at 'NO-SHOW' conferences."
The goal of care, in this instance healthcare, is to look after those who need it so why wouldn't those who need the most care be involved with any discussion of their care?

https://blogs.bmj.com/bmj/2013/08/16/lucien-engelen-patients-not-included/

3. The growing influence of disabled disability activists on Social Media, is proof of the effect of accessible activism. Online creators are able to educate and advocate for the rights of disabled people, when governments do not, in a way that is accessible to them and others. https://mashable.com/article/disability-activists-social-media accounts-to-follow

4. **'Towards a new partnership between disabled people and health and care services: getting our voices heard'** is a very interesting publication by Kings Fund. It lays out how partnership can get our voices amplified and change achieved; and strengthens the case of the need to talk to both groups of people. https:// www.kingsfund.org.uk/publications/partnership-disabled-people-health-care services

5. **'The health care of tomorrow? International learning on community, technology, and avoiding digital exclusion'** is another important article by Kings Fund. It lays out why it is important to not limit information by exclusively accessing it online. It is impossible to build inclusive communities without consider those who do not, or cannot, access online resources. https://www.kingsfund.org.uk/audio video/podcast/health-care-international-learning-technology

6. **Charities and Trade unions** make up a large percentage of organisations pushing for a change in the culture of care. The resources they have could be really useful for us given the time limit we have for this project. Some example that align with what we have discussed as a group are:

   - **Caring for Carers**:they givemedics a place to vent and solve problems while supporting their mental health and wellbeing. https://www.caringforcarers.org/ about.php

   - **The Patients Association**: an independent patient charity campaigning for improvements in health and social care for patients - lots of campaigns and organising. https://www.patients-association.org.uk/mission-and-vision

   - **Health Campaigns Together:** 'is not just another health campaign.It is an initiative to enable many of the campaigns that have been formed to liaise together, share experiences and lessons, and where possible work together on issues of common concern.' https://www.healthcampaignstogether.com/ aboutus.php
   - **Royal College of Nursing**: 'The Royal College of Nursing is the world's largest nursing union and professional body. We represent close to half a million nurses, student nurses, midwives and nursing support workers in the UK and internationally. As a member-led organisation, we work collaboratively with our members to:
     - influence governments and other bodies
     - improve working conditions
     - campaign on issues to raise the profile of the nursing community.' https://www.rcn.org.uk/

5. **AGE UK:** A charity that campaigns for the care of the elderly. Which is the second biggest population needing care after the disabled, a demographic we need to also be inclusive of. https://www.ageuk.org.uk/our-impact/

6. **BMA (British Medical Association)**: represents, supports and negotiates on behalf of all UK doctors and medical students. We are member-run and led, fighting for the best terms and conditions as well as lobbying and campaigning on the issues impacting the medical profession. https://www.bma.org.uk/what-we-do

Research

HOW ARE YOU?!

Basic Overview on Inspiration and Sources behind our Idea to start measuring A National Care Index:

Source: Singapore Medical Journal; Google Scholar.
URL: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4800719/

'Bhutan is a small landlocked country measuring 38,394 km^2,(1) with a population of 745,153.(2) It recently celebrated 108 years of monarchy; however, the country introduced its first constitution in 2008.(3) When the current King of Bhutan, Jigme Khesar Namgyel Wangchuck, was crowned in 2008, Bhutan was transformed into a unitary parliamentary constitutional monarchy.(2) The second and reigning Prime Minister of Bhutan, and the political head of the country, is Tshering Tobgay. Bhutan is divided into three regions (Western, Central and Eastern) and has 20 districts called *dzongkhags*. Bhutan's currency is the ngultrum (Nu) and its value is on par with and pegged to the Indian rupee. The major sectors that contribute to Bhutan's economy are tourism, agriculture, forestry and the sale of hydroelectric power. According to the 2011 National Health Accounts, its gross domestic product (GDP) per capita was USD 2,121.(2) Bhutan is known for measuring its happiness with the Gross National Happiness (GNH) Index.

The term was coined by the fourth king of Bhutan, Jigme Singye Wangchuck, in 1972 to show his commitment toward building the economy in a sustainable manner, based on Buddhist spiritual values and well-being.(4) **The Constitution of Bhutan also expresses the importance of GNH, as it states "*the state shall strive to promote those conditions that will enable the pursuit of Gross National Happiness*".(5)** GNH has four underpinning pillars and nine domains (Fig. 1).(4)

In 2010, the following nine domains and their respective indicators were developed:(3) 1. Psychological well-being: life satisfaction, positive emotions, negative emotions, spirituality.
2. Standard of living: assets, housing, household income per capita. 3. Good governance: government's performance, fundamental rights, services, political participation.

4. Health: mental health, self-reported health status, healthy days, disability.
5. Education: literacy, schooling, knowledge and value.
6. Community vitality: donations (time and money), community relationships, family, safety.
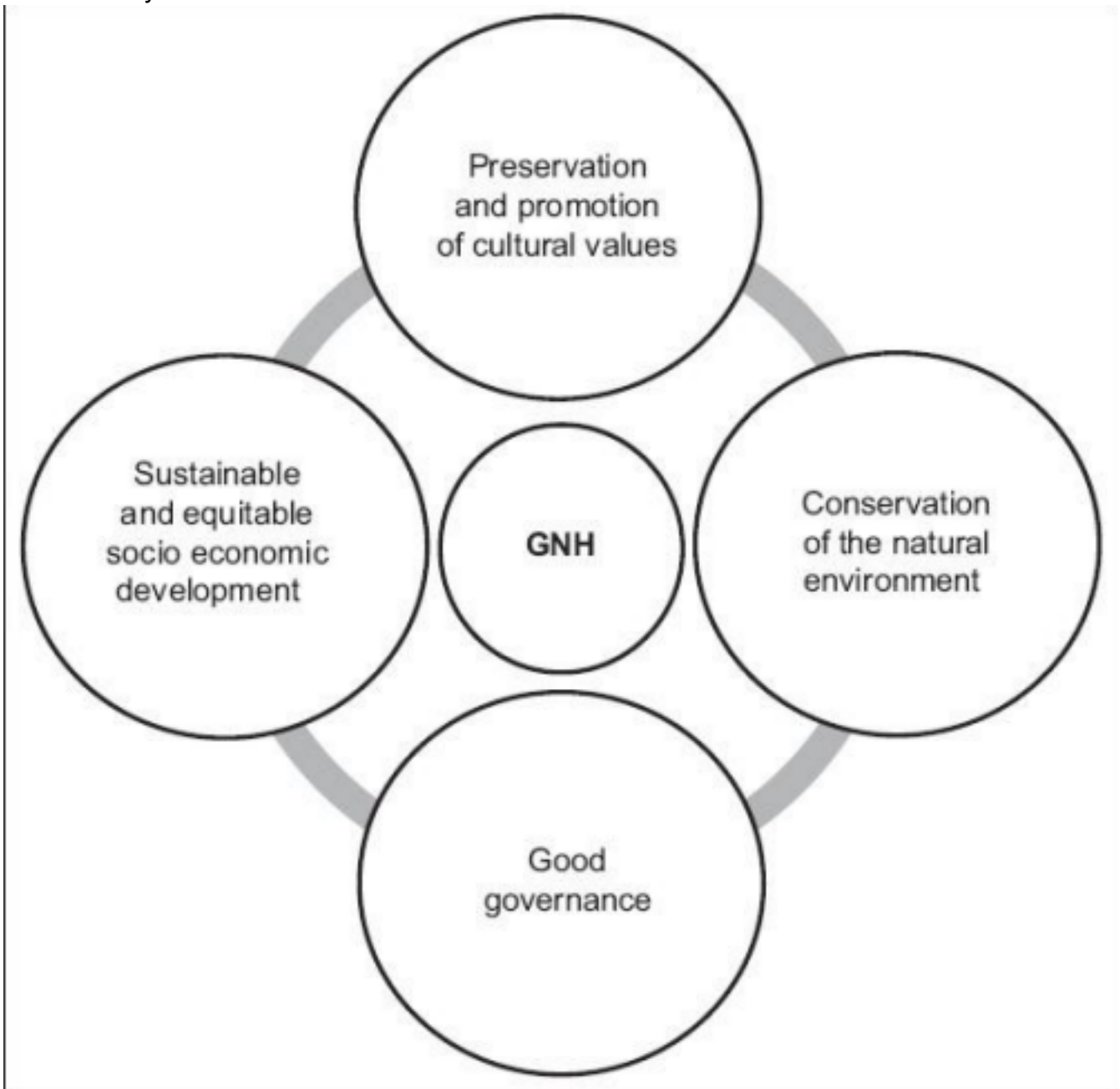

Fig. 1
Flowchart shows the four pillars of Gross National Happiness (GNH).

7. Cultural diversity and resilience: speak native language, cultural participation, artistic skills and *Driglam Namzha* (social etiquette).
8. Time use: work and sleep.
9. Ecological diversity and resilience: ecological issues, responsibility towards environment, wildlife damage (rural), urbanisation issues.

The planning commission of Bhutan was renamed the GNH Commission on 24 January 2008 and new responsibilities were assumed to ensure that GNH would be firmly embedded in policies. As the convergence point for all prospective plans/projects and policies pertaining to Bhutan, GNH is reflected in terms of five-year plans that are implemented by various ministries. The 'Five-Year Plan' system was introduced in 1961 by the third King of Bhutan, Jigme Dorji Wangchuck; its aim was national economic

development. According to the system, the ten ministries of Bhutan and other governmental agencies focus on sectoral development and submit their plan to the GNH Commission for further scrutiny. The GNH Commission assesses the plans based on its individual objectives, National and Sectoral Key Result Areas, and respective Key Performance Indicators, all of which contribute toward the achievement of the four pillars of GNH. The approved plan is then executed by various sectors and monitored in the following five-year plan. Approval from the GNH Commission also applies to new businesses in the private sector.

In 2010, a GNH survey found the following:([4](#))
  • On average, men are happier than women.
  • Of the nine domains, Bhutanese have the most sufficiency in health, followed by ecology, psychological well-being and community vitality.
  • Urban areas tested better for health, living standards and education, while rural areas tested better for community vitality, cultural resilience and good governance. • Happiness is higher among people with primary education or above than among those with no formal education. However, higher education did not greatly affect GNH.
  • The happiest people by occupation include civil servants.
  • Unmarried people and youth are among the happiest'

The Difference we are aiming for is to measure a NATIONAL CARE INDEX as opposed to what most Governments often do - they measure the National Health Index.

Definition of a HEALTHCARE v CARE INDEX:

'Health Index is **an estimation of the overall quality of the healthcare system, healthcare professionals, equipment, staff, doctors, cost, etc**. HealthCare Exp Index - is aiming to show a health care index such that it raises MORE (exponentially) if the healthcare system is of better quality.'

Why not just measure the Health Care Index?

The existing Health Care index model only measures physical accessibility i.e. structures and not the actual quality of care and does not take into account the Human Aspect of Healthcare which is essential in my opinion.
What it Measures :

The Conceptual and Operational Considerations.

  • 2.3.1 Morbidity indicators.

• 2.3.2 Mortality indicators.
• 2.3.3 Indicators of behavioral risk factors.
• 2.3.4 Health services indicator.

Source: https://www3.paho.org/hq/index.php?
option=com_content&view=article&id=14405:health-indicators-conceptual-and
operational-considerations&Itemid=0&lang=en#gsc.tab=0

The Problem with GNHI Index is it is often measuring the negative outcomes of a system without trying to improve it with a more human approach. To count a system within a binary of Life and Death feels accurate but highly problematic.

The reasons for Mortality of Morbidity does not seem to take into account the social factors of a health care system - in the sense of the importance of human community and human interaction.

The factors taken into account are often from the Medical Professions data surveys and not the patience themselves, the care taker etc. It does not factor in the Care of the Medical Professionals.

We are also trying to simplify the Outcome and immediacy of issues —
> Problem to outcome.

One of the many differences and improvements to expand the ideas for a Gross National Health Index is to hope it becomes an index for the every person to hold their political representative's efforts as much as the price of food and gas, as well as to be bring the complicated index into a simpler understanding for the general public to be debated in a public realm.

Visual Inspiration

The visual inspiration and development for our project is contained in an additional PDF. It contains: our Padlets, where we did most of our visual brainstorming for our project; the design development for our posters and marketing; and our Figma, where we designed our posters.
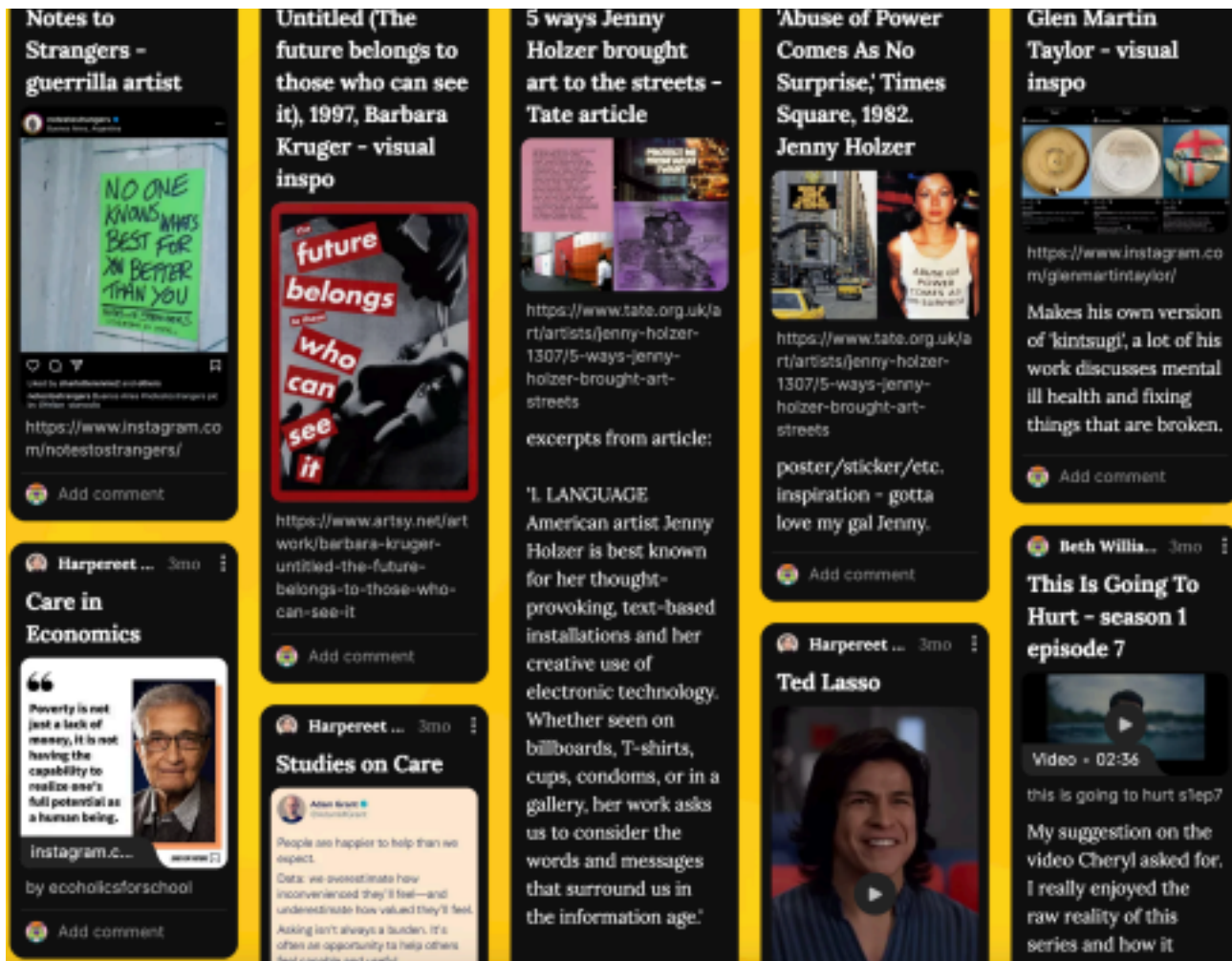
Screenshot from our Padlet, from our visual inspiration PDF.

Some of the topics covered in our visual inspiration are:
- Radical Empathy
- Pedagogy in health and social care
- System failures
- Healthcare activism
- Intersectionality in healthcare inequalities
- Guerilla Marketing
- Welfare of care workers

Ethics Issues

The biggest issue we encountered in our project is the risk associated with asking questions of a sensitive nature. We wanted to collect quantitative and qualitative data on how cared for, or uncared for, people in the UK feel. In our research we have discovered a lot of people we talked to were unhappy with the state of health and social care services and many have suffered because of it. In particular, minority groups feel incredibly overlooked.

We have discussed our personal traumatic experiences of being uncared for, and the response we have received for doing so. Disabled people are often shamed by practitioners and wider society when speaking out. They are accused of causing mistrust in care, discouraging others from seeking help and being ungrateful as the NHS is free to use. We strongly believe in order to gather data about care we have to discuss this issue. It is an issue often left out of any conversation and a vital component to our qualitative research.

This topic is very sensitive. There is risk to respondents re-sharing potentially traumatic experiences, and there is risk to us when reading through these accounts. Carrying out a survey would require specialist training due to the high risk associated with it. We are unable to receive

such training during the AcrossRCA project, therefore we are proposing the full survey that discusses these topics as the outcome for the project. We still wanted to gather some form of data to underline the need for the Gross National Care Index that we are proposing, therefore we had to come up with several solutions to this ethics issue; we also used this as an opportunity to provide more varied research.

The possible solutions we came up with:

- Send out a low risk version of the questionnaire. This would entail removing any high risk questions from the questionnaire. As well as only asking for 'yes/no/unsure' responses on questions that ask about trauma, negative experiences or discrimination.

- Take an auto-ethnographic approach. Members of our group would be the only ones to fill out the questionnaire to give examples of possible responses. These examples would serve as a supplement to the full questionnaire that we are proposing as our outcome. We believe this would be lower risk as we are in control of what we are sharing and what is being shared.

- We will carry out a series of one question surveys that will be linked to QR codes on our visual outcomes. These will be overriding questions, such as 'Do you feel cared for?'. These questions will give us quick quantitative data points we can use to support the need for a Gross National Care Index

- We can ask for non-traditional responses to our questions - for example, we would provide respondents with a series of images, or other articles of media, and ask which one best fits how they feel in response to the question we ask.

- All the questions on our questionnaire will be made optional, this will be clearly highlighted at the start of each section along with a brief description of what will be asked and discussed. This allows respondents to opt out of anything they may find triggering. It also improves the accessibility of the questionnaire as some respondents may have difficulty with attention, fatigue or comprehension caused by disability or other factors.

The solution we landed up using was to send out a low risk version of the questionnaire to gather some initial data to support our proposal. We went through the full questionnaire and ranked the questions as low, medium and high risk. We completed an ethics review based on this and proposed to omit the high risk questions. We were able to include the medium risk questions by mitigating the ethical issues.

Medium Risk

Please respond to each potential risk

	No	Yes
8. Involves animal participants	✔	
9. Takes place outside the UK	✔	
10. Offers financial or other forms of incentives to participants	✔	
11. Involves the discussion of topics that participants may find distressing.		✔
12. Causes a negative impact on the environment beyond normal daily activity	✔	
13. Involves deception and/or the collection of data without the consent of participants	✔	
14. Involves gathering or preparing non-living biological samples not already held in a university, museum or other collection?	✔	

Screenshot of medium risk section from our ethics review.

The mitigation's we put in place were:
• To allow responses to be submitted anonymously.
• Providing an opportunity to opt out of any question that the respondents don't feel comfortable answering
• Each question comes with a description of the possible triggers discussed to help respondents opt out before psychological harm is caused.
• We made it a requirement for each respondent to provided informed consent, through a consent form, before being able to access the questionnaire.

On top of carrying out this lower risk questionnaire with members of the public, the four members of our group filled out the full questionnaire were are proposing as our project outcome. These examples would serve as a sample responses for the Gross National Care Index. We were able to provide these response as we could personally take on all the responsibility of harm caused by possible distressing topics.

We submitted all of this information to the ethics review committee before taking any action to gather responses. Despite identifying a potential medium risk the committee found our mitigations were satisfactory and cleared us to carry out the project with no further ethical complications.

Risk Breakdown of Questionnaire

This is how we categorised the ethical risk of each question as detailed above. Low and medium risk were part of the questionnaire we presented to the public, whereas the high risk questions are only included in the questionnaire included in our proposal.

Key:
Low Risk
Medium Risk
High Risk

Questionnaire: Gross National Care Index: do you feel cared for?

The aim of this questionnaire is to gather quantitative and qualitative data on how cared for, or uncared for, people in the UK feel.

'The Caring Society theme investigates the practical and philosophical dimensions of health and well-being, and how we can shape society to be more effective in the processes of care. Each section will give a brief description of what is being asked. Please only fill in what you feel comfortable too. You can skip any question if you need to. The only question that we require to be filled in is **'Do you feel cared for?'.**

Sub-themes of this theme include: health and wellbeing, neurodiversity, mental health, inclusive design, social model of disability, healthcare, medicalisation, pandemics, death, ageing society, worker rights, mistreatment of employees and patients.

Part 1: Personal Information - please only fill in what you are comfortable sharing.

This section asks for personal information - please only fill in what you are comfortable sharing. It is also where you will consent to your information being gathered and used by us.

Name:

Age:

Occupation:

Country/location:
1. Do you feel cared for?

This is the only question we are requiring to be answered in order to participate in this questionnaire.

Please skip through any sections you do not want to answer, or completely answer, by clicking next until you are asked to submit your response.

- Yes

- No

- Unsure

Part 2: Caring Society - please only fill in what you are comfortable sharing.

This section asks if you believe we live in a caring society and if you feel you're cared for individually. It also gives you the option to explain your answers if you would like too, and offers you the option to suggest what improvements you would like to see in our society.   Please only fill in what you are comfortable sharing.

We are defining a **caring society** as: a society that treats all who require health and social care with equal dignity and respect. That ensures everyone can access the care they need on equal footing with others despite their identity, background and actions. A caring society is also one that

values, repeats, looks after and protects any person that works and volunteers to care and support others.

1. Do you believe you live in a caring society?

- Yes

- No

- Unsure

2. Can you explain your previous answer?

……

3. Do you believe society cares for you as an individual?

rank: 1 (not cared for at all) to 10 (completely cared for)

4. Can you explain why you believe this?

……

5. How do you think society could become more caring?

……

Part 3: Your Experience with Health and Social Care - **please only fill in what you are comfortable sharing.**

This section will ask about whether you work in health or social care, if you are a carer, and if you are someone who requires health and social care.

Please only fill in what you are comfortable sharing.

1) Do you work in health or social care, or consider yourself a carer?

- Yes

- No

- Unsure

2. If yes please specify what kind of care you provide (select all that apply to you):

- I am a healthcare professional (eg: doctor, nurse, psychologist, physical therapist, healthcare assistant, etc.)

- I work in social care (eg. Care worker, social worker, advocacy worker, driver or transport managers, activities worker, etc.)

- I volunteer for in health and social care

- I work or volunteer for a health and/or social care charity

- Unpaid career (someone who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and

cannot cope without their support).

• Other, please specify:

Are you someone who requires health or social care support?

• Yes

• No

• Unsure

4. If you are comfortable sharing, why do you require health or social care support (select all that apply to you)?

• I am disabled or have a long term health problem (physical or mental)

   • I require treatment, aftercare, control or prevention of for a disease, illness or injury.
• I am elderly

• I require support in order to care for others

• Other, please specify:

Part 4: Caring for for those that need it - please only fill in what you are comfortable sharing.

This section is aimed towards people who receive/have received health and social care. It asks about the general quality of care in our society as well as the quality of care you have personally received; whether that be positive or negative.

The first half of the questions can be answered by anyone, however the second half is for those who receive/have received health and social care.

It also specifically asks if you have been discriminated against within care services. However, you will not be asked to provide any details about individual instances of abuse or discrimination.

There are options to expand on your other answers if you want to, as well as the opportunity to suggest what improvements you would like to see in our society.

Please only fill in what you are comfortable sharing.

1. As a society do you think we do enough to provide care to those that need it?

• Yes

• No

• Unsure

2. Can you explain why you believe this?

….

3. How do you think society could provide better care for those who need it?

….

4. Do you believe the current health and/or social care systems that exist are accessible to you? *Please only answer if you're someone who has health and social care needs

- rank: 1 (not accessible for at all) to 10 (completely accessible)

5. Can you explain how current systems are accessible or inaccessible to you? *Please only this answer if you're someone who has/has had health and social care needs:
….

6. Do you feel like your current needs are being met? *Please only this answer if you're someone who has/has had health and social care needs.

- Yes

- No

- Unsure

7. Can you explain why you believe this?

….

8. Please rate your overall experience of health and/or social care?

- Excellent

- Very good

- Good

- Fair

- Poor

9. Can you please give some examples of your most impactful interactions of health and social care?

……

10. How has wider society treated you as someone who requires health and social care?

……

11. Have you felt discriminated against, or treated unfairly, as someone who requires health and

- Yes

- No

- Unsure

12. If yes, and if you feel comfortable doing so, can you explain how you have felt discriminated against?

……

13. Is there a group or person, within wider society, you feel most cared for and supported by? Can you please give some detail? *Please only this answer if you're someone who has/has had health and social care needs:

…..

 Part 5: Caring for our Carers - **please only fill in what you are comfortable sharing.**

This section is aimed towards people who provide/have provided health and social care. It asks about the general support available to care providers as well as the quality of support you have personally received; whether that be positive or negative.

The first half of the questions can be answered by anyone, however the second half is for those who provide/have provide health and social care.

It also specifically asks if you have been discriminated against within care services. However, you will not be asked to provide any details about individual instances of abuse or discrimination.

There are options to expand on your other answers if you want to, as well as the opportunity to suggest what improvements you would like to see in our society.

Please only fill in what you are comfortable sharing.

1. As a society do you think we do enough to support our health and social care workers, and/or carers?

- Yes

- No

- Unsure

2. Can you explain why you believe this?

….

3. How do you think society could provide better support for our health and social care workers, and/or carers?

…..

4. Do you believe the current health and social care systems are causing unnecessary harm or distress to health and social care workers, and/or carers?

rank: 1 (Extreme amounts of harm caused) to 10 (No harm caused at all)

5. Can you explain why you believe this?
….

6. Do you think you receive enough support to allow you to care for people to the best of your ability?

- Yes

- No

- Unsure

7. Can you explain why you believe this?

….

8. Please rate your overall experience of the care/support you have received as a health and social care worker, and/or carer? *Please only this answer if you're someone who provides/has provided health and social care needs

- Excellent

- Very good

- Good

- Fair

- Poor

9. Can you please give some examples of your most impactful interactions where you have felt supported, or unsupported, as a health and social care worker, and/or carer? *Please only this answer if you're someone who provides/has provided health and social care needs

……

10. How has wider society treated you as a health and social care worker, and/or carer? *Please only this answer if you're someone who provides/has provided health and social care needs

……

11. Have you felt discriminated against, or treated unfairly, as someone who requires health and social care? *Please only this answer if you're someone who provides/has provided health and social care needs

- Yes

- No
- Unsure

…..

13. Is there a group or person, within wider society, you feel most cared and support by? Can you please give some detail? *Please only this answer if you're someone who provides/has provided health and social care needs

…..

14. How could society care better for you, as someone who is a health and social care worker, and/or carer?

…..

Part 6: Caring in our current climate - please only fill in what you are comfortable sharing.

This section is aimed towards everyone. It asks about how you believe current events have changed how caring our society is.

The current events that are asked about is the Covid-19 Pandemic, the rise in global inflation and financial instability, and how mass media discusses the topic of care.

There are options to expand on your answers if you want to, as well as the opportunity to suggest what improvements you would like to see in our society.

Please only fill in what you are comfortable sharing.

1. Do you think the Covid-19 Pandemic has caused society to become more or less caring?

Rank 1 (less caring) to 5 (more caring)

2. Can you explain why you think this?

……

3. Do you think the current global rise in inflation and financial instability has caused society to become more or less caring?

Rank 1 (less caring) to 5 (more caring)

4. Can you explain why you think this?
……

5. Do you believe the media (news, music, movies, education, etc.) and social media helps society become more or less caring?

Rank 1 (less caring) to 5 (more caring)

6. Can you explain why you believe this? Please use an example if possible.

…….

7. What kinds of local support groups do you think would be beneficial for a carer? E.g: exercise classes, therapy etc.

……

8. Are there any other societal issues you believe affect how caring our society is?

…….

9. What actions do you think should be taken to improve how society cares about you and/or others?

…….

Accessibility of Online Survey Tools

The accessibility of our questionnaire was incredibly important. Many people who require health and social care are disabled or have health conditions. Due to this they may have access needs that we need to address, so as many as possible can contribute to the Gross National Care Index.

We have made every question in the survey optional, apart from 'Do you feel cared for?', so those who struggle with concentration or fatigue can participate without having to fill in the whole thing. There will also be a printable PDF that can be requested incase someone does not have access to technology, or are uncomfortable using it.

We plan to gather most of our responses through an online survey tool as they're generally easier to gather and sort information through. However, before we went live with questionnaire we did research into many different survey tools to make sure we were using the most accessible one. Below is a summary of the research we preformed.

Google Forms

Google Forms is a survey administration software included as part of the free, web-based Google Docs Editors suite offered by Google.

Positives:
- You're able to change colour, contrast levels and fonts - making adjustments to what is easier for the respondent
- Zoom in up to 300% without text spilling off the screen - readable large text •
Can be used with a keyboard
- Can be used with speech recognition software
- Can be used with screen readers - including latest versions of three most popular (JAWS, NVDA and Voice Over).
- Tested accessibility, with client side error checking.

Negatives:
- Buttons, labels, tabs and instructional text may not have good enough colour contrast for everyone.
- Tables column and row headers aren't always clearly identifiable
- Form builder can be difficult to use - not an issue for respondent but wanted to include anyway
  - Certain tooltips (the boxes with information that comes up when you hover your cursor over it) aren't fully accessible to keyboards and screen reader users.

Microsoft Office Forms

Microsoft Forms is an online survey creator, part of Office 365. Forms also allows users to create surveys and quizzes. Any data collected can be exported to Microsoft Excel.

Positives:
- You're able to change colour, contrast levels and fonts - making adjustments to what is easier for the respondent
- Zoom in up to 200% without text spilling off the screen - readable large text • Can be used with a keyboard
- Can be used with speech recognition software
- Can be used with screen readers - including latest versions of three most popular (JAWS, NVDA and Voice Over) - however this is not automatic, the creator is responsible for it.
- Tested accessibility, with client side error checking.

Negatives:
- A lot of the features are reliant on creator - we may miss something • Known bugs with screen readers
- Microsoft have disclosed their software is not fully accessible and needs improvement
- Doesn't work well with all browsers

Qualtrics

Qualtrics is a sophisticated online survey platform on the planet. It's used a lot in research published in journals as it also analyses the data.

Positives:
- Can ask a brand admin to create an accessible theme - incredibly expensive, but expert.
- Simple accessible layouts

Negatives:
- No visible difference between certain question types
- Does not indicate whether a field is required or not
- No client side error checking
- Screen readers are always accurate due to quirky code
- Increased accessibility costs a lot of money
- Process of making it is not accessible at all

Survey Monkey

A free or paid tool to create surveys, quizzes, and polls. Responses can be gathered via weblink, email, mobile chat, social media, and more. It also provides analysis if wanted.

Positives:
- Provides guidelines on how to make surveys accessible

Negatives:
- Claims to be compliant with accessibility guidelines however this is untrue - they're currently being sued for this so probably best to avoid this tool.
- Dodgy code, makes it harder for screen reader and speech recognition users •
Very low colour contrast

Catalyst WebQ

Previously known for being accessible but not the software has been retired. They do however recommend Google Forms and Microsoft forms.

Conclusion

After careful consideration we decided to launch our online questionnaire with Google Forms as it has the most accessibility features and is compatible with most common accessibility tools. We were also to mitigate most of the negative factors. We able to do this through not using the question types that weren't fully accessible with screen readers and speech recognition software. The form builder being difficult to use was not an issue as we are working in a group, so we could get support if one of us had trouble using it. The only issue we were not able to fully mitigate was the colour contrast not being good enough for some with visual impairments. We chose the colours with the highest contrast. However, given as this was the only issue, the accessibility offered by Google Forms was far better than any of the other online survey tools.

Sources:
- https://www.gov.uk/government/publications/dft-accessible-online-form-and-survey statement/accessibility-statement-google-forms
- https://students.hud.ac.uk/media/universityofhuddersfield/studentsx27website/ hudstudy/MicrosoftForms-AccessibilityStatement.pdf
- https://www.webaxe.org/surveymonkey-web-accessible-or-not-not/ • https://www.accessibility.com/digital-lawsuits/brittney-surveymonkey-02/09/2021
- https://itconnect.uw.edu/tools-services-support/software-computers/catalyst-web tools/webq/
- https://www.surveymonkey.co.uk/mp/508-website-accessibility/

Peer Feedback

The feedback we received from our peers focussed on the possibility of us narrowing the scope of people we planned to reach with our questionnaire. It was suggested that we pick a specific demographic of people within the UK rather than everyone. We understood the concern of focusing on such a large scope was that we were possibly prioritizing quantity over quality. The feedback was fair, we knew effectively appealing to everyone was going to be considerably harder and more time-consuming. However after much discussion we decided that we would rather work harder if it meant we could reach a higher level of inclusion. Despite the difficulties that come with having a wide target audience, avoiding feelings of exclusion was too important to our mission to sacrifice it to save time. It was one point of discussion that came up when our team first came together. We feed this back to our peers and we believe we effectively justified our large scope.

The inclusion we achieved is one of the highlights of the Gross National Care Index. We appreciated every time someone brought a possible blindspot to our attention, and worked effectively to find a solution. It made our project stronger and gave us knowledge we can take into our personal practices.

Data Analysis

Even though our sample size was small due to the ethical issues around the topics we need to survey, the results show that half of those questioned feel uncared for or are unsure of how cared for they feel. This data was sufficient to suggest that we have stumbled onto elements that need to be further addressed. The full set of data we collected is contained within separate PDF's for each version of the questionnaire.

Do You Feel Cared For?
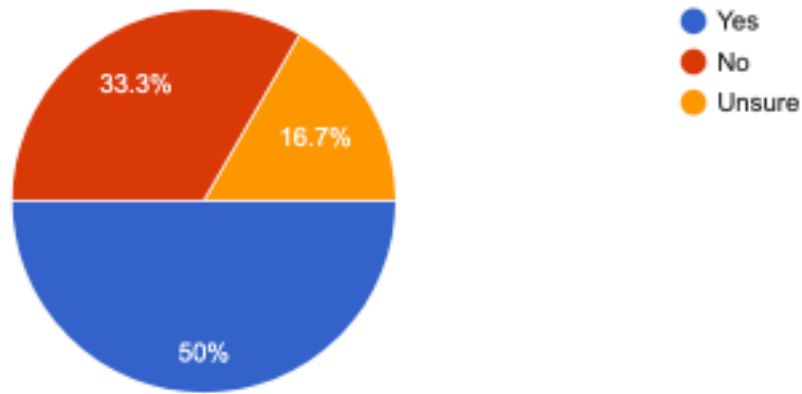
Screenshot of data collected from our Low Risk questionnaire, from separate PDF.

When asked whether they feel like that they live in a caring society, a resounding 75% indicated that they DO NOT. The weight of belief that society cares for you as an individual sits closer to the negative than the positive thus showing that being feeling cared for as an individual is not highly recognised or felt.

The split between those who need care and provide care are even and given that, those giving care are unpaid and often family work and support. There seems to be a consensus from those surveyed that we need to provide care for those who need it. We are very aware as a whole that we are not providing adequate support to those who need it as a society simply by hearing of family care and family support talking people out of the workforce or just adding to an individual burden.

Do you believe we live in a Caring Society?
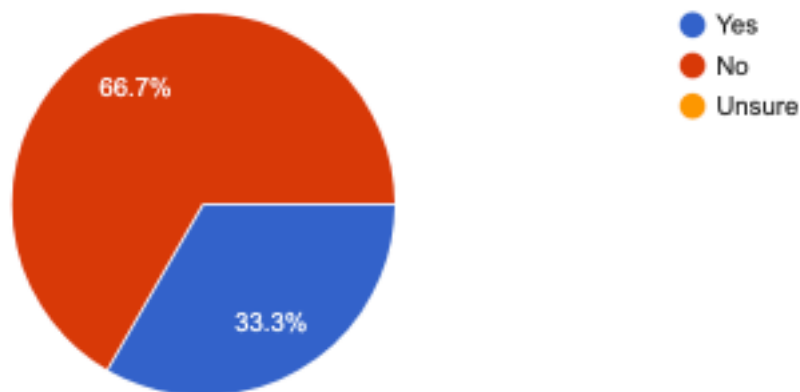
Screenshot of data collected from our Low Risk questionnaire, from separate PDF.

In conclusion, so many of the responses feel like enough to thoroughly dive into such a
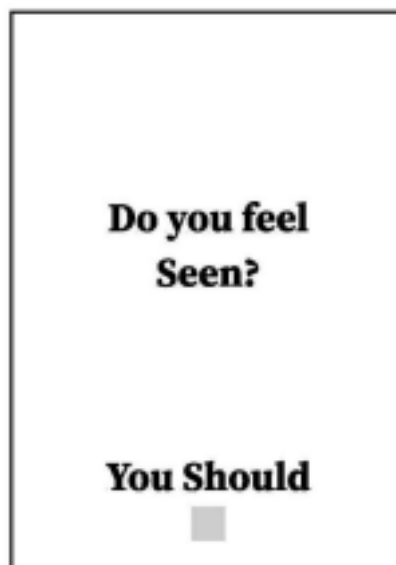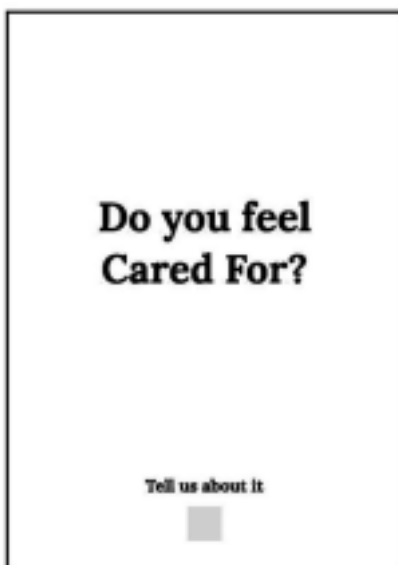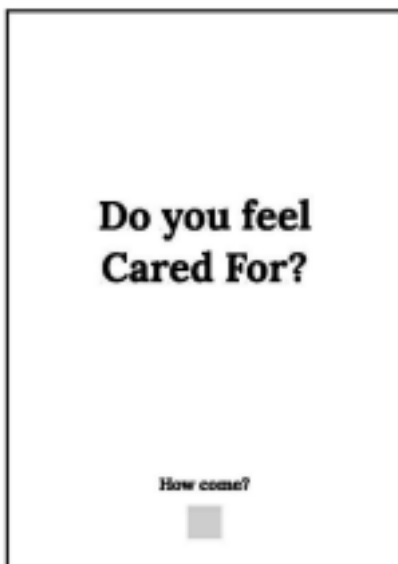
topic to quantify the problem for it to be legitimised by our political institutions and addressed as a whole for a better civil society.

MARKETING MEDIA AND QR CODE

Design & Poster Inspiration

Our design approach was to appear as simple and DIY as possible to achieve a relatable look and approachable look. By moving away for over design, glossy and flashy adverts we were hoping to show a folk-ish, honest and human-like media campaign. Something that would have been able to be replicated at home with just a photocopy machine. We chose to include hands as our only image to underscore this. Having a personal touch was important to us so our audience feels comfortable sharing possibly triggering topics.

Do you feel Cared For?

How come?

Do you feel Listened to?

What helps?

Do you feel Cared For?

Tell us about it

Do you feel Seen?

You Should

We are all very inspired by the poster and graphic artist Landon Sheely and launched from that vibe to create very block printed, graphic heavy, font and space dependent posters that gave the look of being very simplistic but gave a very powerful presence if seen on the street or inserted into a folded newspaper. Very reminiscent of Yoko Ono and John Lennon's newspaper print during the anti war movement.

We included a QR code at the bottom of each poster as it's the fastest way to access our questionnaire. It's simple, does not detract from the posters design and is graphic like many of our design inspirations. All of our design development and final posters are in our external visual PDF.

Tactile Posters

As well as our graphic poster designs we also designed some tactile textile posters. Not everyone engages through just sight, they may find other sensory experiences more inviting. This is why we developed our textile posters, they are designed for people who prefer to engage through touch. They are also still flat enough that they could be scanned in to enhance our graphic posters.

Our tactile posters. Left: lace crochet poster; Right: cyanotype print poster.

During our project we did not have access to a Raster Braille tool to create braille versions of our graphic posters for those with vision impairments. Our tactile posters helped us create something that visually impaired people could engage with, without specialist tools. This helped us make our project accessible to even more people.

Social Media

We used Instagram and TikTok to market our project. We chose social media as its accessible, an easy way to start a conversation and quickly get our message out there.

Using different types of social media in our campaign gives us access to different audiences, and help extend our reach. However, it did mean we had to create different posts for these audiences by playing into the trends presents on each platform. These videos can be found through the content sheet of our submission.

Left: screenshot from Instagram post
Right: screenshot from TikTok post

For Instagram we went with a simple video that directs people straight to our questionnaire. As the audience on Instagram usually prefers more polished and curated content. Whereas for TikTok we used the process involved with making the tactile posters as their users prefer rougher, 'behind the scenes' content. We made sure both videos used captions and narration so it was accessible those who are visually/hearing impaired.

The main purpose of the social media posts is the drawn users towards the questionnaire. However, we also used it to build awareness and start a conversation. Seeing peoples initial reaction to the question 'Do you feel Cared For?' was incredibly helpful. Many who commented said they did not feel cared for, which strengthened our viewpoint hat this is an area that needs improvement.

Do you feel Cared For?
Tell us about it.