

# Beyond biomedicine

## Principles for future healthcare design



---

# The current challenge



The COVID-19 pandemic has placed pressure on health systems across the world at an unprecedented scale. In the UK and abroad, COVID-19 has created a need to rapidly find solutions and create future resilience, as well as highlighting the reality of health inequalities across the country.

The pandemic has shown that it is not enough to deal with the health of individuals in isolation from the wider social influences that determine people's experiences of health. There are many complex factors that impact on an individual's experience of their own health. In the context of needing to 'build back fairer' (see [COVID-19 Marmot Review 2020](#)), health-related research that seeks to address underlying inequalities, has never been so important.

**Our health issues, and the ways we treat them, are often put into a box.**

---

In order for these significant challenges to be overcome, this briefing argues for greater collaboration between researchers, policymakers, funders and those with lived experience of different health conditions. We draw on a diverse set of examples to offer those looking at future healthcare design and delivery ideas about what a fairer, more person centred approach to health could involve.

## Health as holistic

Biomedicine, more commonly known as 'conventional' medicine, has characterised the health system in the UK for many years. It tends to prioritise the understanding and treatment of biological and physiological effects of different conditions, and views health as 'good' or 'bad', with responses managed in clinical settings.

At Durham University we do great biomedical research. We also look at how behaviour, environment, culture, economic status and many other factors influence health. By intergrating this understanding with the biomedical model, we begin to understand not only health conditions, but how to support health holistically.

Such a perspective leads to more personalised treatment, more proactive prevention, and enables us to reach and engage groups in the population that are left behind in more traditional approaches.

Only in this way will we be truly able to move the focus of healthcare away from the biomedical factors that cause disease and the ubiquitous reactive approach to ill-health.

Our enquiries seek to include factors that support human health and wellbeing and understand our experience of health and ill-health. By drawing on the human experience of health, we can translate this knowledge base into practical and cost-effective approaches to guide the decision pathway of clinicians, clinical commissioning groups (CCGs), local and national public health bodies and international non-governmental organisations.

Our approach is enriched by meaningful engagement with the public. We include a breadth of stakeholders, and engage with the public as people invested in their communities and local networks. In doing so, we widen the discourse, developing solutions that go beyond those that reach 'most of the people most of the time'.

## Principles for thinking about future healthcare

We believe the following principles, informed by our research and exemplified in the case studies that follow, offer an alternative perspective for future healthcare design:

### ■ Address local and individual contexts

Refocus funding, research, and discourse from disease and treatment systems to those that consider health in its broadest sense, including the wider social structures that influence it. For example, what influence do place and the environment have on health, ill-health and recovery?

### ■ Adopt an integrated approach to research, development and delivery of care and support

Bring together different research disciplines, stakeholders and perspectives to understand the experience of health in people's daily lives.

### ■ Prioritise lived experience

Ensure that those accessing support from the health system are seen not just as 'patients', but as people with different lived experience of health and wellbeing. By taking a rounded view of individuals and their lives, it will be possible to uncover mediatory routes to treatment and arrest unhelpful approaches.

### ■ Challenge entrenched inequalities in resources, access, and outcomes, and the systems that perpetuate them

Develop policies and services that work for those in the toughest circumstances, working with and to change structures that influence health.

## Principles in action:

# 1 New approaches to treat breathlessness

**Understanding people's individual experiences of their own health is fundamentally important to developing appropriate responses.**

Breathlessness is a common and debilitating symptom suffered by people globally. It largely affects people in marginalised communities because of its association with smoking and air pollution.

The clinical approach seeks out pathology first and foremost, needing to diagnose in order to determine the appropriate treatment. In the case of chronic breathlessness, however, this approach is often ineffective as specific treatments are not curative and the problem inevitably worsens. This is especially the case with chronic obstructive pulmonary disease, the third most common cause of death globally, which is steadily progressive and has few effective treatments.

At Durham, in the Life of Breath project we investigated what it is like to live with breathlessness. We found that people associate the symptom with negative thoughts and feelings which can make the symptom worse. Understanding people's individual experiences of their own health is fundamental to developing appropriate responses. We discovered that there is a complex interplay between the physical sensation of breathlessness, people's life experience and their thoughts and feelings. This interrelation can make it difficult to design approaches to support people living with breathlessness.



Through a pilot project, co-designed with a breathlessness support group, we discovered that dance classes under the care of a suitably trained teacher, address some of this complexity. Dance is fun, sociable and non-threatening. It reconnects people with chronic breathlessness with their bodies in a way that enables them to enjoy their physicality rather than see it as a burden. This has clear significance for tackling the current and future 'long-COVID' health challenge in both adults and children, where breathlessness is a defining symptom.

The main evidence-based treatment for chronic breathlessness is pulmonary rehabilitation, which is carried out on an individual basis in a gym-like space. Dance by contrast connects people with breathlessness to past enjoyable experience and by dancing a group can support each other's progress.

### **To find out more:**

**Visit the [Life of Breath](#) project website. Project led by Prof Jane Macnaughton at Durham University and Prof Havi Carel at the University of Bristol. Supported by teams at both Bristol and Durham Universities and expert collaborators.**

## Principles in action:

# 2 Skills not pills: community-based pain self-management

There is a need for understanding the individual experience and person-centred management. For those with persistent pain, the sustainability of 'fit-for-purpose' health systems (including training), the potential for families and the community to offer support, and the experiences of people living with pain mean that a different way of thinking about health and care is required.

Persistent pain is a huge health challenge. It is the biggest reason people in the UK see their GP. The World Health Organization recognised it as a priority disease in 2019. The National Institute for Health and Care Excellence (NICE) has also recently accepted that current chronic pain medications have limited use, and in fact carry serious safety concerns. That is why reducing opioid prescriptions (for non-cancer pain) to zero by 2024 is a priority for Public Health England.

Pain is a bio-psycho-social phenomenon that cuts across social, primary care, public health and rehabilitation. Healthcare professionals realise the need to change how they engage with people with persistent pain. Persistent pain cannot be 'fixed' or 'cured'. It needs an understanding of the individual experience and person-centred management, to help people live better lives with it. The sustainability of health systems must be re-evaluated. There is potential for families and the community to offer support, and improve the experiences of individual pain-livers. A different way of thinking about health and care in pain management is required.

Durham's '**Skills not pills**' approach comprises a 'Gabapentinoid and Opioid Tapering Toolbox' (GOTT) and App. This offers a set of tools to improve confidence of primary care clinicians and pharmacists and their patients to self-manage chronic pain.



## NICE National Institute for Health and Care Excellence

This type of approach has been endorsed by NICE ([ITV News](#), April 21)

### To find out more:

The '**Skills not pills**' project is supported by our newly launched virtual platform: [Footsteps Pain Festival](#) (e-social prescribing), developed and hosted by the [Live well with pain](#) team and Durham University.

## Principles in action:

### 3 Enlighten healthcare spaces: the natural way

Even in highly clinical settings such as intensive care it is possible to be more sensitive to individuals' sensory environment, view perspective, engagement needs and preferences. This can reduce the feeling of isolation, formality and seriousness, therefore reducing the potential for anxiety, distress and delirium.

**“It is the unqualified result of all my experience with the sick, that second only to their need of fresh air is their need of...not only light but direct sunlight.”**

*From 'Notes on Nursing' by Florence Nightingale*

Intensive Care Units (ICU) have garnered a lot of attention during the COVID-19 pandemic. Their function and design are focused on infection control. They are stark and devoid of natural light. In this environment there is a strange combination of sensory deprivation, due to a detachment from the familiar, and sensory overload, as a result of 24/7 lighting 'pollution', constant activity of medical staff and 'alarming' machinery sounds. This can be detrimental and disorientating to patients, staff and visitors, especially after long periods.

The Enlighten Programme brings together several disciplines and the community (ICUsteps) to address how the physical environment and access to natural light impact our health, well-being and recovery, and what changes can be made to improve this. The project focuses on the clinical nature of hospital environments, particularly ICUs. The project explores whether the experience of the ICU community (patient, carer and staff) can be improved by introducing personalised 'natural' lighting, sound and other sensory and aesthetic changes.



Alongside innovative information and communication technology for internal and external re-engagement, these changes can be implemented in the future design of hospitals and clinical settings. The project also explores the possibility of integrating the dedicated interior and exterior 'sensory garden' intensive care space available 24/7 for the benefit of the ICU community.

#### **To find out more:**

You can read more about the [En'Light'en](#) project of the **Wolfson Research Institute for Health and Wellbeing at Durham University**.

## Principles in action:

# 4 Parental mental health and baby sleep: gaps in policy and practice

Lack of integration often means that issues are looked at individually rather than holistically. For example, disrupted sleep and fatigue are common issues for parents in early infant care. This situation has potentially significant knock on effects on children, yet guidance on this is largely absent from ante-natal and post-natal care pathways.

Poor parental mental health is a public health crisis costing £8.1bn per year. Despite recent efforts to prioritise funding for maternal mental health, policy regarding support during early parenthood has lacked integration, and has over-looked prevention. Disrupted sleep and fatigue are common challenges for parents in their baby's early life, yet both are absent from antenatal and postnatal care pathways, as well as early-life programmes, with patchy support across services.

Research conducted at Durham University's Infancy and Sleep Centre found that sleep disruption and fatigue during their baby's first-year affected parents' mental health, emotional stability, relationships, and ability to accomplish responsibilities within and outside the home. Parental inability to cope with sleep disruption also had repercussions for infant



health, safety, and responsive care. Moreover, primary care and front-line staff lacked evidence-based knowledge, training and tools to confidently support parents struggling to cope with normal infant sleep.

Our 'Sleep, Baby and You' approach offers a training solution for practitioners and a support programme for parents that joins up parental mental health needs with responsive infant care, emphasising the importance of integrated policies and care pathways for parents and infants.

### To find out more:

Visit the [Sleep, Baby & You project website](#).

The website provides resources for parents, as well as tools and training for practitioners. Developed by Professor Helen Ball and Dr Catherine Taylor (Durham University Infancy & Sleep Centre) and Dr Pam Douglas (Possums Education).

## Principles in action:

# 5 Understanding voices

**Interdisciplinary and cross-sector collaboration is critical to developing more integrated, empathetic responses. Actions toward integration include greater use of the arts and humanities to understand questions of clinical concern, foregrounding personal experiences and accounts of particular health issues, as well as incorporating insights from care providers.**

Up to 1 in 10 people hear voices that others don't. It is an experience that is commonly associated with distress, with mental illness, and shame linked to social stigma. Voice-hearing can also be part of everyday life, arising in contexts ranging from spiritual devotion to creative practice.

**Hearing the Voice** is a large interdisciplinary research project that has been investigating this phenomenon since 2012. Our work combines insights from anthropology, cognitive neuroscience, history, linguistics, literary studies, medical humanities, philosophy, psychology and theology, with perspectives from artists, clinicians and people with lived experience.

The website, **Understanding Voices**, was produced by Hearing the Voice in partnership with voice-hearers, representatives of leading NHS trusts and mental health charities. It presents literary, historical and spiritual perspectives on voice-hearing alongside psychological and neuroscientific research, information about



therapies, personal stories and practical tools for living with voices. Recommended by Rethink and Mind, the site is now a key resource for NHS staff and provides voice-hearers and their families with access to coping strategies and sources of support, as well as normalising and non-stigmatising ways of understanding their experiences.

Further improvements to mental health practice have been achieved through clinical training and an award-winning digital health intervention for the management of unusual sensory experiences (MUSE), which is now used by Early Intervention in Psychosis services across the North of England.

### To find out more:

See the **project's infographic** and visit **Understanding Voices** and **Hearing the Voice**.

## Principles in action:

# 6 Evaluating e-therapies in the community

**The rapid transition to online ways of working and interacting presents new opportunities for the delivery of healthcare in virtual settings, while enabling personalised responses that adapt to people's individual contexts.**

Brain injury invariably has consequences for behaviour, such as the loss of speech, movement or cognitive ability. Whilst neurorehabilitation techniques are in widespread practice for these impairments, those who experience visual loss after brain injury have been less well served by the NHS.

We have developed DREX (Durham Reading and EXploratory) training in collaboration with patients, their carers, and various health professionals such as consultants, occupational therapists and nurses. This e-rehab is helping patients in the UK and beyond to compensate for their impaired vision thereby helping them to re-engage with everyday life, improve their quality of life, and lessen service demand on the NHS.

This is an online rehabilitation programme, and we are evaluating its use in a holistic sense, investigating factors that can affect its uptake and efficacy such as loneliness, multimorbidity and support. By understanding the patient's needs, condition, aims, targets and surroundings, we can achieve a patient-focused approach to rehabilitation that is of economic value to the NHS.

### To find out more:

Visit the [DREX website](#) to learn about the free-to-download app for sufferers of partial visual loss. DREX training can be used to compensate for partial visual loss following stroke or brain injury.

Get in touch with us for further information by emailing [drex.training@durham.ac.uk](mailto:drex.training@durham.ac.uk).

## Overall recommendations

- To develop a more holistic approach to healthcare, we need a more holistic way of viewing health needs, experiences and underlying determinants. This includes engaging a broad range of stakeholders, including those with lived experience, in development of new approaches and crucially, in training the next generation of researchers and practitioners to think differently about healthcare.
- A reliance within current biomedical approaches on randomised control trials often fails to take account of individual experiences of health and wellbeing. A focus on the value of a broader base of health research, including from humanities subjects, that helps to understand these experience and narratives is crucial to building a fairer healthcare system.
- It is important that future reforms of the health system look beyond structures and how to organise 'treatment'. Instead, a focus on principles of fairness and local context when designing policy, should seek to address underlying societal determinants and inequalities that impact on individual experiences of health.

## To work with us:

At Durham we believe we live these values through our research, teaching and supportive learning environment. To work with us contact the:

- **Wolfson Institute for Health and Wellbeing Research**  
[wolfson@durham.ac.uk](mailto:wolfson@durham.ac.uk)
- **Institute for Medical Humanities**  
[imh.mail@durham.ac.uk](mailto:imh.mail@durham.ac.uk)
- **Biophysical Sciences Institute**  
[admin.bsi@durham.ac.uk](mailto:admin.bsi@durham.ac.uk)

Document created in collaboration with the Research Retold team at [www.researchretold.com](http://www.researchretold.com) (2021)