Health equity project posters

by Cohort 2 Fellows

Sussex Health&Care

KSS Health Innovation Kent Surrey Sussex

NHS Sussex

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The Intersectionality of Inequity in Contemporary Healthcare

Clara Clein Wolfe. *Spine Team: Patient Care Advisor. Personalised Care Champions Team: Trauma Informed Care Champion.*

Population health is declining. A complex interplay of factors influences health outcomes.
In her 2016 TED Talk, Kimberlé Crenshaw spoke about her theory of intersectionality in which different aspects of social justice issues, such as race or gender, overlap, or *intersect*, creating multiple levels of injustice compared to when aspects are solely seen in isolation [https://www.ted.com/talks/kimberle_crenshaw_the_urgency_of_intersectionality].
This Sussex Health Equity Fellowship [SHEF] project explored the intersectionality of inequity in contemporary healthcare.

Background.

- **Lived experience of iatrogenic outcomes** from inequitable medical treatment inspired this project, in addition to repeated issues seen as an administrator/by the administrative team.
- The 10 Core Principles of Health Equity allowed a range of factors to reflect upon throughout the project: ***people, data, care, clinical, digital, finance, place, climate, policy***, and ***communication***.
- Administrative daily tasks, such as, raising referrals, sending rejections, and actioning/chasing diagnostics reveals a lot of medical communication and medical ***miscommunication***.
- Exploring health inequities through the eyes of an administrator provided insight into the barriers of the wider healthcare system concurrent with the direct impact this has on individual patients.

Assessment.

- Examples and patterns of health inequity are presenting daily and taking a toll on all involved parties.
- A small number (N=7) of anonymized case studies were captured and reviewed.
- ***Communication*** issues were important in *every* case intersecting with other principles leading to inequity in healthcare. For example, systemic assumptions about technology access and capacity, and complicated jurisdictional issues leading to patient confusion/distress.
- Additionally, ***trauma*** was especially prevalent in the cases and is an increasingly significant factor impacting patients' capacity to engage with services, attend diagnostics, and self-manage. Therefore, **contributing** to further health inequities and **intersecting** with the core principles.
- Trauma issues are impacting the workforce as demonstrated by sickness levels and attrition.

Recommendations.

- All case studies demonstrated that biopsychosocialtechno [biological, psychological, social, technological] factors of a person's lifeworld intersect in myriad ways.
- The shame that comes with some past traumas needs to be reflected upon in wider clinical contexts.
  - For example, if a patient has repeated instances of not attending, reviewing their medical record can sometimes reveal an issue which may be driving this behaviour
- Curiosity and an open mind are a crucial aspect of care.
- Health communication needs to be written in clear, simple language.
  - Campaign for Plain English [https://www.plainenglish.co.uk/] offers advice and accreditation for services. Additionally, beta testing with populations with, for example, learning difficulties, neurodiversity, English-as-a-second-language, could identify issues otherwise not considered.
- Making assumptions in healthcare is leading to inequity.
  - Therefore, it must not be ***assumed*** that everyone has a smartphone nowadays, has mobile data/Wi-Fi, is literate, has capacity to manage their health, is able to discern between *'Dr Google'/TikTok/influencer culture* and useful/verified information, has the resources to attend appointments, has support outside the clinic room, has access to meaningful-to-them information, and has the ability to meaningfully convey their symptoms/engage in appointments to support their health.
- Cross-service cooperation is in everyone's best interests.
- **Agility** in practice could improve outcomes. For example, offering more virtual appointments if patients are unable to attend, supporting patients with additional requirements, and investing in staff wellbeing.
- **Reflective practice** has merits for ***all*** staff.

Reflections.

- As someone with medical CPTSD, a difficult history with healthcare, and multiple illnesses, caution should be taken in generalising from this project. Conversely, the benefit of those with ***lived experience*** should not be dismissed.
- Across the SHEF program the direction of this project was impacted by ill health and evolved into an exploratory project, plus a ***starting point*** for a larger piece of work on ***trauma intersecting core principles of health equity***.
- Issues of intersectionality and trauma do not solely impact patients. As healthcare paradigms shift and change, it is vital to be ***caring for all our staff.***
- **Trauma informed care** is expanding in contemporary healthcare following the revolution of Personalised Care, shared decision making, and asking ***what matters to you***, not *what is wrong with you?,* can reduce health inequities/reduce barriers to health.
- Curiosity, reflection, and continued research are important to further the knowledge about inequities in healthcare to eliminate them.

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Improving patient outcomes through SDOH assessment in clinical practice.

Claire Lockwood, Service Manager – Urgent Community Response. East Sussex Healthcare Trust (ESHT).

The Problem

Social Determinants of Health (SDOH) are the non-medical, economic, and social factors that influence health. Up to **60%** of health outcomes are attributed to these factors—where individuals are born, grow, live, work, and age.

At ESHT, **adverse SDOH can lead to longer hospital stays** due to reliance on emergency services and increasingly complex social needs. Currently, healthcare systems often use area-level data (e.g. postcodes) to assess equity, but this can obscure individual experiences. Collecting SDOH information at an individual level allows for **more personalised care, improved clinical decision-making, and better health outcomes.**

Recognising that this gap in practice was impacting patient care, I initiated a project to understand staff readiness, identify barriers, and design practical interventions to embed SDOH assessment into routine clinical workflows.

The Background

A baseline survey of 131 healthcare professionals at ESHT was conducted to explore staff perspectives and guide the implementation of SDOH assessment. The survey assessed **knowledge, attitudes, and current practices around SDOH**. Most participants recognised the value of collecting SDOH information during patient encounters. Staff with more **training and experience** reported greater familiarity with SDOH concepts and **fewer barriers** to integrating them into practice.

The Intervention

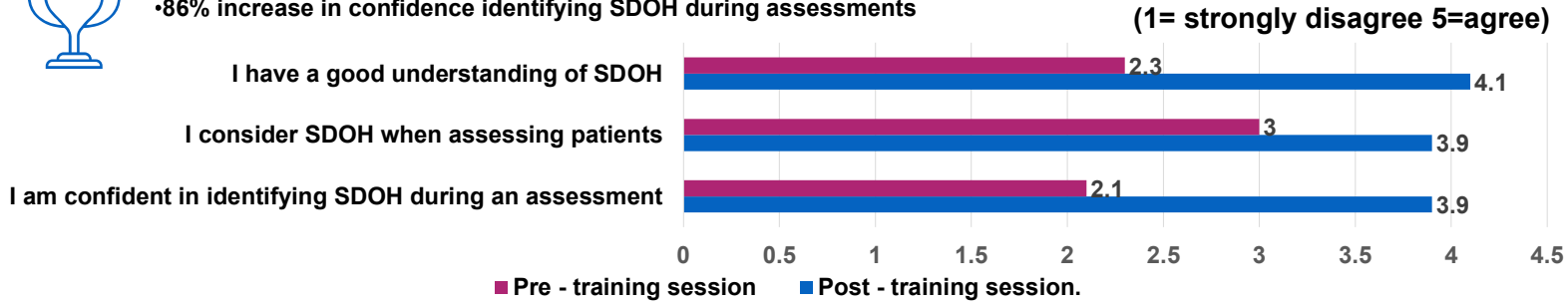
By September 2025, we aim to embed SDOH assessment into routine clinical practice at ESHT through the following actions:

- **Deliver in-service training on SDOH** to increase awareness, confidence and skills in identifying SDOH. (by April 2025)
- **Support clinicians in applying inclusive SDOH assessment**, focusing on high-priority settings. (by May 2025).
- **Implement a screening tool** to flag patients with adverse SDOH who may require enhanced inpatient support (by September 2025).

The Achievements

In April 2025, a one-hour training session on SDOH was delivered to clinicians. Evaluation showed:

- **78% increase in understanding of SDOH**
- **30% increase in consideration of SDOH during patient assessment**
- **86% increase in confidence identifying SDOH during assessments**



The Future

- Continue **offering SDOH training across ESHT**, with focused support for the HIT team. This **will improve staff confidence** to assess and address social needs, resulting in **safer discharges and reduced readmissions**.
- Adapting existing SDOH screening tools for ESHT will ensure consistent **identification of social risks**, enabling timely support.
- Implement a clear triage process for patients with adverse SDOH, will ensure rapid connection to support services leading to **more stable outcomes.**

Our Goal - Allocating resources proportionately—more for those who face more challenges.

High intensity users of emergency care

Making their care bespoke, equitable & relational

Dr Christopher Odedun
Consultant in emergency medicine
University Hospitals Sussex (UHSx) East
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High intensity user patients (HIUPs) = frequent, complex service users with high impact and unmet needs
Key #Core20plus5 group due to deprivation and complex health & social issues
Sussex ICB funds a third-sector HIUP emergency care service - but demand far exceeds capacity.
Governance burden (aggression & incivility, incomplete care episodes, poor experience) are high

The project supports the 10-year plan's shift to prevention and community care, and work has focused on three key domains:

Data

- Comparison of 'top 50' HIUP cohorts in 2024 & 2025, mapping their demographics & current patient-specific plans (PSPs)

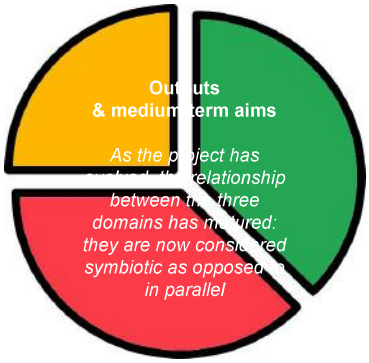
Education

- Extensive stakeholder engagement
- Training ~30 ED staff in creating a psychologically informed environment for HIUPs

Operations

- Identification of inadequate governance practice, aiming to improve visibility of PSPs & 'flags' in electronic healthcare records

Word cloud taken from training session for ED staff, March 2025



Stakeholder mapping examples

Neurodivergence: use of a local clinician-researcher's unpublished findings on high prevalence of autism in crisis health mental population, to inform need for personalised emergency care

Homelessness & substance misuse: close working with Pathway & CGL team in the ED, leading to momentum around need for MDT meetings

Common Ambition: discussion around how best to involve experts by experience in service design

UHSx Mental Health Quality & Safety Group: presentation of needs assessment to meeting, chaired by UHSx Chief Medical Officer, Feb 2025

Data

- Improve capture, to report unmet HIUP need effectively to ICS commissioners
- Report quarterly to UHSx stakeholder groups

Education

- Use successes (newly awarded consultant jobplan time & recruitment of population health fellows) to extend HIUP training offer to 95% of ED staff
- Co-create HIUP pathway (analagous to stroke/trauma) with experts by experience

Operations

- Audit & implement EHR flags + PSPs
- Join up HIUP hospital services across Sussex
- Restart MDT meetings for PSP creation

Challenges

Scale & Complexity

HIUPs are a complex, heterogeneous patient group; sustaining measurable progress is difficult, and the burden of need is high

Continuity

Early work on data collection stalled due to unforeseen absence of other staff working on the project

Ethical Engagement

Involving experts by experience risks reactivating trauma; careful, ethical approaches have been needed, requiring outside expertise

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Understanding and Addressing Barriers to MSK Health

With a specific focus on neurodivergence, mental health and learning disability

Georgia Aloof, Sussex MSK Health, Advanced Practitioner

Musculoskeletal (MSK) health in the UK is marked by significant inequalities influenced by socioeconomic status, ethnicity, gender, and age. These disparities affect not only the prevalence of MSK conditions but also access to care, treatment outcomes, and overall quality of life. This project is grounded in a commitment to improving musculoskeletal (MSK) services through a lens of equity, lived experience, and inclusive practice. The work addresses both systemic challenges and individual experiences by integrating data, lived voices, staff insight, and operational collaboration.

Insight Through Design and Lived Experience

Analysis including qualitative and quantitative data in the MSK service reveals disparities in MSK care outcomes and patient experiences, particularly for individuals with neurodivergence, learning disabilities, and mental health needs. I therefore decided to focus on these population cohorts, and through networking, was invited to speak with the Neurodivergent Lived Experience Advisory Panel (LEAP). I decided to focus on how we could improve the beginning of the journey – accessing MSK health, and how we can ensure the sense of a safe and calm environment, with a particular focus on Community Appointment Days (CADS) and What Matters To You Hubs – existing projects aiming to improve patient care.

"There needs to be more warning about what to expect. I believe someone with anxiety, mental health or a neurodiverse condition would really struggle with the big and busy environment."
(Patient Feedback: Horsham CAD)

Not an ideal setting for someone with anxiety/autism. Very loud, lots of people. Very overwhelming.
(Patient Feedback: Crawley CAD)

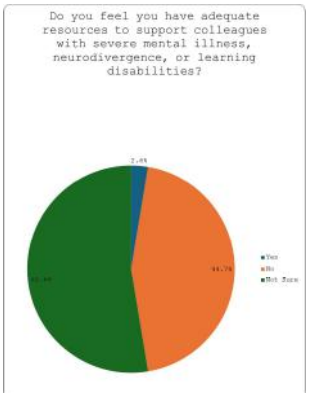
Data demonstrated that far fewer individuals attending a CAD event identified themselves as requiring reasonable adjustments or as having a disability than the local census population data.

Actionable Recommendations – LEAP/Stakeholders

Accessible Information	• Clear early information with visuals (pictures, videos, maps) which could include walkthrough video and sample Q&A
Supportive Guidance	• Digital support, buddy systems, and empathetic staff trained in neurodivergence and reasonable adjustments for wellbeing
Comfortable Environment	• Low sensory environment with natural light, private breakout rooms, and ensured privacy
Right size and facilities	• Welcoming, small setting with refreshment options, easy transport access and flexible scheduling

Staff Survey, Staff Development and Cultural Change

I then created a staff survey to assess awareness and confidence in supporting patients and colleagues with learning disabilities (LD), neurodivergent conditions (ND), and severe mental illness (SMI). Results showed varied understanding of reasonable adjustments, health inequities, and how to support these groups. Staff also reported lacking adequate resources. In response, I'm developing structured teaching on MSK links with mental health, learning disabilities and neurodivergence. I am also looking to deliver teaching on equitable care, while also focusing on staff wellbeing. I have also met with pathway leads within the MSK service to feedback responses. I'm collaborating with the ICB, who are producing bite-sized modules on how best to support neurodivergent individuals (and additional needs) in healthcare.



WHAT NEXT?

- Ensure above findings are embedded in our day to day care
- Consider a 'Reasonable Adjustment' specific CAD event
- Community engagement to ensure easy and direct access to care
- Support with project around health literacy/MSK health in areas of greatest deprivation, as well as ongoing 'What Matters To You Hubs'
- Teaching to colleagues within MSK Health on health inequity
- Support the ICB training for professionals

LESSONS LEARNED?

- Importance and challenges of data collection and interpretation
- Essential nature of stakeholder involvement and engagement
- Complexity and multifaceted nature of health inequity
- Talking about health inequities raises awareness + sparks change
- CADS and What Matters To You Conversations have the capacity to enable equitable healthcare access and engagement

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Hyper-Localised Mobile MSK Units

Jessica Crowe ~ Training Coordinator D&I ~ Sussex MSK Health (Here) ~ June 2025

Addressing barriers to accessing treatment for musculoskeletal conditions among non-white individuals and those in lower socio-economic groups in Brighton, Hove and Crawley.

NHS
Sussex MSK Health
Brighton & Hove and West Sussex

The Equity Challenge

Barriers to accessing treatment for musculoskeletal conditions among non-white individuals and those in lower socio-economic groups in Brighton, Hove and Crawley. How do we work with people we have identified as having a MSK need but the system is not meeting?

Measuring the Scope

- People with language barriers sit on the MSK waiting list longer than English Speakers.
- A person is twice as likely to DNA an appointment if they are non-white (19% of referrals, 38% of DNAs) and/or in the lowest socio-economic decile.

Primary Goals

- To reach communities we know are not following up on their MSK care with a mobile MSK unit
- To work with the organisations in place within the communities already doing the work, a co-created response
- Agility, mobility and adaptation

The intervention is a mobile 'pop-up' MSK unit staffed by a physiotherapist or Advanced Practitioner, a Care Navigator, and an Administrator. It offers treatment, referrals, diagnostics, and exercise plans; supports joined-up care and community signposting; and manages logistics and patient data. The model is scalable, with potential to operate in settings like places of worship, libraries, sheltered housing, workplaces, leisure centres, and parent–baby groups.

Scalability:
Warehouses
Gatwick Airport
Food Banks
Mother & Baby Groups
Libraries
Places of Worship

Lessons Learnt 1

As a test run for the mobile MSK Mobile Unit idea, I assisted with a community outreach clinic in Crawley Mosque. While everyone was incredibly welcoming, I quickly realised that I might not be the most appropriate person to lead such a programme in this setting. My limited understanding of cultural sensitivities, gender dynamics, and the value of established community trust highlighted that this role would be better suited to someone embedded within the community and who has a better understanding of their specific needs.

Lessons Learnt 2

This experience also made me think more broadly about other community settings—like food banks and places of worship—where I might not be the right person to lead a project, and where it makes much more sense to work alongside people who are already part of those communities, and understand their needs better. Engaging with stakeholders, including Patient Partners, clinicians and leadership, I also explored how this project could be scaled to reach people we know are affected by MSK conditions but struggle to access care—like the baggage handlers at Gatwick who often can't get to a clinic or fit an appointment around their shifts. I realised the importance of working not just with stakeholders within my own organisation, but also with trusted community leaders, whose involvement is vital in shaping services that are respectful, relevant and accessible. I plan to measure the success of the project through feedback surveys and by whether we're invited back to run further sessions, as this will show both impact and trust within the community.

The Future

The learning I have garnered from these experiences and from speaking with stakeholders will inform the shape of the future of my project by ensuring that community voices are central from the outset, and that the design and delivery of each project setting is done in partnership with people already in those communities. Using the model of Community Appointment Days, we will make sure the project is grounded in real community need by utilising those connections within each community. As a result of this approach, my organisation Sussex MSK Health is already planning to visit the baggage handlers at Gatwick Airport who often cannot fit appointments around their shifts, and holding Care Navigator conversations in local cafes to make these appointments more accessible. I plan to measure the success of the project through feedback surveys and by whether we are invited back into these community groups to run more 'clinics'.

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Improving access to physical health care for those diagnosed with a severe mental illness (SMI)

SMI = Bipolar, Psychosis, Schizophrenia, eating disorders, emotionally unstable personality disorder (1, 6)

Author: Karen Hartley
Population Health Academy
Health Equity Fellow Cohort 2 2024/25

Background

The prevalence of long-term conditions (LTC) amongst those diagnosed with an SMI is disproportionately high compared to the general population (1,2) . Life expectancy is 15-20 years shorter, and cause of death is often linked to physical health conditions and potentially preventable (6). Prevalence of LTC are higher than the general population, and onset is usually at a younger age (1,2,3). Medication prescribed for SMI lengthens life, however side effects contribute to fewer years in good health (2). The group is more likely to terminate treatment plans early compared to other groups due to a lack of trust in services and traumatising experiences of health and care services (7). Activities and investment in supporting increased access to physical health care does not appear to have had a positive effect on the life expectancy of the group, and there remains an inequity in outcomes. **This project aimed to explore why and identify interventions to address them.**

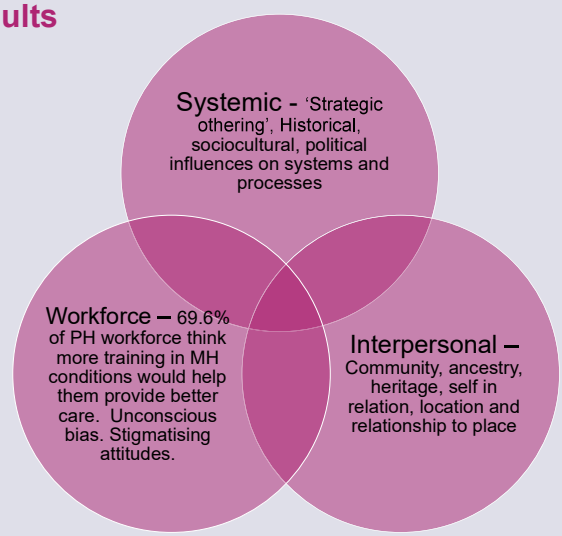
Data (1,2,3,6)

- Uptake in physical health checks for SMI are increasing. Target is 60%, Sussex currently at 57% (Q2 2024/25)
- Life expectancy **15-20 years shorter** than general population and **growing wider**. Those aged 15-34 likely to have 3 or more physical health conditions.
- **SE has highest indicator value for excess deaths of any region**
- **People with mental ill health had higher rates of preventable admissions & used less planned care(6).**
- **71% of emergency use was for physical health needs (6).**
- 5x higher rates of liver disease, 4.7 x higher rates for respiratory disease, 3.3 x higher for CVD 3 x increased risk of cancer, 3x more likely to lose their natural teeth
- Deprived areas have a higher prevalence of SMI.

Method

- **Rapid Literature Review:** Published peer reviewed (11) and grey literature (8). CINAHL, Cochrane, PubMed.
- **Analysis** using a social justice philosophical position, influenced by Kant and moral philosophy tradition**.**
- **Lived Experience:** explored results with groups with **lived experience** of SMI and those who deliver care to those with SMI in physical health care settings to review analysis.
- **Results:** Workforce are asking for support to provide care for those with SMI and MIH. Those with lived experience see the workforce struggling to meet their needs.
- **Interventions** designed across three areas 1) Epistemic Injustice 2) Stigma and Discrimination and 3) Critical Self-Inquiry
- **Recommendations** considering the intersectionality of the group and the resulting uniqueness of local and global context.
- **Limitations:** Not research, gatekeeper to access lived experience, assumptions of intersectionality based on literature.
- **Ethics**: Respect for the person, lack of evidence on ethics of co-production as an approach.

Results



Results

Interventions

1) Developing Mental Healthcare skills in PH workforce training – training package running in Sussex, additional training developed and cascaded.
2) 2) Developing Physical Healthcare skills in MH workforce training – next stage of work.
3) 3)Diagnostic Overshadowing Training Resource designed for testing and roll out.

Discussion & Recommendations

1.Epistemic Injustice – Refers to a wrong done by someone in the position of a knower. Both testimonial and hermeneutical injustice was evident(4). The way in which HCPs are educated and encultured into professional identities appears to contribute to this. Lack of MH knowledge amongst the PH workforce leads to a lack of confidence and missed opportunities for interventions.

2. Recommendation: review of theory and practice in pre and post registration learning to consider how unconscious and unspoken messages of stigma, and discrimination are transmitted and embedded in practice

3.Stigma and Discrimination - hermeneutical injustice refers to someone being unable to understand or express an important aspect of their experience due to a gap in shared tools of social Interpretation(4).

4.Recommendation: health literacy of the population needs to be improved to enable a better understanding of lived experience. This will support greater co production and person centred approached to care.

5.Critical Self-Inquiry – Testimonial injustice refers to the credibility of another being reduced due to prejudices we hold about the speaker(4). HCPs lack opportunities to interrogate their own belief systems in a safe environment for growth.

6.Recommendation: health care professionals are encouraged to critically inquire into their own patterns and ways of knowing, and to interrogate the assumptions they make about the person they are treating.

References: 1) Public Health England, 2018Severe mental illness (SMI) and physical health inequalities: briefing - GOV.UK ; 2) NHS England 2025. NHS England » Improving the physical health of people living with severe mental illness3) NHS England Digital Physical Health Checks for People with Severe Mental Illness - NHS England Digital; 4) Luong,V. et al. 2024. Unravelling epistemic injustice in medical education: The case of the underperforming learner - Luong - 2024 - Medical Education - Wiley Online Library 5) 2014 Hankivsky Intersectionallity 101.pdf 6) 1540147713_qualitywatch-mental-ill-health-and-hospital-use-summary.pdf 7) Tyerman,J. 2020. How stigma and discrimination influences nursing care of persons diagnosed with mental illness: a systemic review.

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IMPROVING HOSPICE ACCESSIBILITY

Breaking down deterrents to use of hospice services, supporting the shift from hospital to community settings

Lois Howell
Chief Executive, St Wilfrid's Hospice

Stage one of a project to identify and address actual and perceived barriers to engaging with hospice care experienced by underserved groups

Articulating the concern

- Engagement with hospice services improves patient experience and outcomes in end of life care
- People from marginalised groups are less likely to engage with hospice services
- St Wilfrid's Hospice wants to identify and overcome actual and perceived barriers to engagement

Assessing the scale

- Assessment of inequity was frustrated by inconsistent data quality
- Two key contributors were found
  - The set up of the tools for data collection and use
  - Limited organisational / cultural awareness of the importance of equity, in comparison with equality

Addressing the fundamentals

EQUITY > EQUALITY

- The patient administration system (PAS) has been revised to enable
  - easier access to data held
  - clearer labelling of absent data
  - prompts to complete absent data
- Training refocussed on equity, diversity and inclusion, rather than equality and regulatory compliance

Context

- To optimise equity of access and outcomes St Wilfrid's sought to assess whether the demographic profile of patients / service users was statistically different to the local population, so that any deterred / excluded / disenfranchised parts of the community could be identified.
- Comparison was attempted, but data collection was found to be inconsistent, leading to incomplete information and consequently poor quality insights and knowledge about the community characteristics of the St Wilfrid's patients / service users

Investigation

- The tools for data collection and data use were reviewed
- Structured discussions with sample clinicians responsible for data collection were held

"I don't need to ask because **my care will be the same**"

"I'm going to **treat everyone the same**, no matter what"

Findings

- The data collection tool provided was structured so that
  - Demographic data collection was not mandatory
  - The completeness of demographic data was not easily visible
  - Collected data was not visible without interrogation
- St Wilfrid's policies and training had traditionally focussed on equality of offer/treatment, rather than equity of opportunity/outcome.
  - Anecdotal evidence of individuals' views corroborated this approach.
  - Training materials had been updated in 2023, but were still equality focussed

Action Implemented

Data collection: From 01.04.25 the tool was revised to

- flag incomplete data fields
- options within each field were updated
- Recording of multiple options within each field was enabled.
- Content of completed fields was made visible without interrogation.
- **Training**: Training material has been revised to emphasise the importance of equity of opportunity and outcomes, rather than avoiding discrimination, and EDI has been incorporated into induction training for all employees and volunteers.
  - Mandatory annual 'Equal opps' training replaced by contexualised awareness raising, focussed on the benefits to all of an opportunities / outcomes approach to EDI, and driven by the work of a cross-organisational EDI Working Group, chaired by the CEO
  - Presentations on the reasons for / importance of demographic data collection in all contexts delivered
  - A 'Foundations for Line Managers' training module was introduced in 2023, including a section on EDI
- **Profile raising**: Relevant risks added to the corporate risk register and considered at Board meetings, plus update from EDI Working Group

Next Steps

Demographic data collection will be monitored throughout 24/25 and reported quarterly to the Clinical Services Committee of the Board

If improvements in data completeness are achieved, the collected data will be used to complete a comparison with census data / general practice demographic profiles (Stage 2 of the programme)

Any inequities in access or outcomes identified will inform development of a plan to understand and address the underlying causes (Stage 3)

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Cervical Screening

12% of eligible women in Rural Rother are not attending screenings

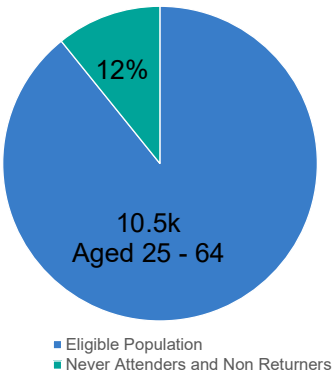
Lauren Walbrin, Care Cooranditor, Rural Rother PCN

The Problem

- To understand the reasons behind the high percentage of never attenders and non returners with in the cohort.
- Barriers may include Working age patients, childcare, appointment availability, patients from deprived areas, Neurodiverse patients and carers.

The cohort

- The population of Rural Rother PCN is roughly 22,000 female people
- Some patients live in the most deprived areas of including Eastern Rother and North West of Rye



Key Stakeholders

GP and Nurses	• Having a positive working relationship with meaningful communication
Healthwatch	• View to working with them in the future
Bruderhoff Community	• Key lines of communication established

Barriers

- Progress is dependent on GP processes including winter pressures and year-end busy period.
- The cohort is always evolving with new patients reaching screening age / moving into the cohort area.
- Collaboration and co-design, with clinical staff buy-in, are essential for the project's viability
- Patient feedback – currently no available survey tools

Next steps

- To be able to monitor and collate patient feedback through surveys/ questionnaire
- To build a relationship with the Bruderhof community to understand and address their barriers for current and future collaboration.
- Engage further with clinical teams involved across practices
- Roll-out the project to the remaining five practices – not yet involved in the project.

The solutions

- Continues improvement through Patient feedback / training
- Design a leaflet / web page which will be available to all patients and staff within the cohort.
- Close working relationships with practices to ensure screening is available across the cohort.
- Regular monitoring of screening uptake addressing.

Lessons Learnt

- The fellowship has taught me to approach projects with a renewed vision. I'll continue to use the skills learnt for future projects/challenges.
- Having learned about the different project models, I determined that the Agile style was the most suitable approach for this project

RURAL ROTHER PRIMARY CARE NETWORK

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Improving mouth care for people with learning disabilities

Co-designing a patient portal

Michelle Asbury, Operational Head of Community Dental Services, SCFT

Research shows that people with learning disabilities face poorer oral health. There are physical, psychological & social consequences of poor oral health & it can have a major impact on people's quality of life. We had an opportunity to develop a **patient portal to provide better access to special care dentistry & personalised oral health resources** to support better mouth care. The project aimed to research if this would be beneficial and, if so, proceed to co-design an accessible portal.

The Evidence

Research shows that people with learning disabilities experience:

- Higher levels of gum disease
- More missing teeth & higher plaque levels
- Greater unmet oral health needs
- Poorer access to dental services & less preventative care
- Toothlessness

There is a clear need for reasonable personalised adjustments in dental care to ensure equitable outcomes.

The Stakeholders

- Patients in the Special Care Dental Service with a learning disability
- The software supplier, Systems for Dentists (SfD)
- SCFT's Equality and Diversity Lead
- Clinical Lead for Learning Disabilities
- Special Care Dental & Oral Health Promotion teams
- Patient Engagement leads
- SpeakOut advocacy service
- Patients' carers
- SCFT Learning Disability advocates with lived experience

The Idea

To determine if co-designing an accessible & relevant patient portal can address the health inequalities people with learning disabilities face.

The impacts of which include:

- Pain & discomfort
- Associations with heart disease, diabetes, respiratory diseases & stroke
- Negative self-esteem, problems communicating, socialising & smiling
- Trouble eating & being well nourished
- Dental anxiety

Outcome: a portal to reduce dental anxiety & improve oral health literacy though shared personalised resources. Self-booking convenient appointments.

Progress

1. Literature review - Barriers to access & impacts of poor oral health care.
2. Baseline analysis of patients with an identified learning disability in the Special Care Dental Service & a patient survey.
3. To do: Co-design & review if a co-designed patient portal improves this picture after 6 months of use.

Table 1: Baseline Data

Measure	Patients	%
Caseload	2786	100
Attended last appointment	2366	85
Cancelled last appointment	171	6
Did Not Attend	104	4
Short notice cancellation	6	0.2
Cancelled by Clinic	119	4

Survey results

254 responses (9%) from people with learning disabilities and supporters about how they contact the dental team & what works best.

Key findings:

- Most people contact the dental team **to book a visit (243)**, to report a dental problem, cancel, or ask for advice.
- **46% (118 respondents)** said they'd like to help **design a new tool** to support people with learning disabilities.

Most people responding have **digital devices** at home:

- **Mobile phones** – 207 people
- **Tablets** – 128 people
- **Computers** – 112 people.
- **21 people** said they **do not use any devices.**

When asked about digital accessibility tools **124 people** said they **don't use any tools.**

- Some people use:
  - **Text-to-speech software** (28)
  - **Speech recognition** (18)
  - **Screen readers** (15).

The results highlight the importance of traditional contact methods but also show interest in improving & developing accessible digital tools for the future. **Next step: Co-design**.

Patients and their carers told us they want:

Toothbrushing tips
Step-by-step instructions, visual guides, and advice on the best toothbrushes and toothpastes

Diet guidance
What food and drinks to avoid, when to consume them

Support for additional needs
Help with brushing for children with sensory issues, autism or ARFID
Social stories and visual aids were highlighted as beneficial

Professional input
Regular check-ups and demonstrations from the dentist or therapist

Resources
Booklets, posters and age-appropriate materials can help to build confidence

Challenges

- Existing patient portal experienced reliability problems following upgrade - delayed the co-design work.
- Developing cultural competency - support from SpeakOut running focus groups with health advocates and advice from SCFTs Learning Disabilities team was invaluable.
- Collecting personal details – The Trust's approved survey method was withdrawn so I was unable to identify volunteers' names or contact information within responses & had to rely on separate contacts.

References:

1. GOV.UK. 2025. Oral Care and People with Learning Disabilities. https://www.gov.uk/government/publications/oral-care-and-people-with-learning-disabilities
2. GOV.UK. 2021. Inequalities in Oral Health in England: Summary. https://www.gov.uk/government/publications/inequalities-in-oral-health-in-england.
3. Gilbert, David. 2019. The Patient Revolution: How We Can Heal the Healthcare System. London: Jessica Kingsley Publishers

Improving Breast Screening uptake in Ethnic Minority Groups

Exploring barriers to attend screening and improving Breast Screening uptake

Rebecca Corbett, Quality & Improvement Manager at University Hospitals Sussex NHS Foundation Trust

Objective: Improving Breast Screening uptake in Ethnic Minority groups and exploring barriers to attend in West, East Sussex, Brighton and Hove Breast Screening Services.

Purpose

Research has shown that some individuals within society are less likely to attend Breast Screening. Studies have suggested that uptake is lower in ethnic minority communities, particularly South Asian Women.

- To work with key stakeholders to explore the barriers for clients attending Breast Screening locally in Ethnic Minority Groups.
- To review local data available to understand the highest ethnically diverse areas in Sussex, collaborating with key stakeholders to engage with diverse communities to tailor approaches that resonate.
- Review the invitation process in Breast Screening and what is available to clients.

Barriers to attending

* Referenced from Act on Cancer Together insight report September 2024

- Lack of understanding of Breast Screening
- Fear and Anxiety
- Lack of time due to personal and work responsibilities
- Cultural beliefs and stigma
- Language barriers
- Inconvenient appointment times

Challenge's

Language: The service sends out timed invitation letters in accordance with national breast screening programme guidance. These letters follow a standardised format that cannot be altered and are currently only available in English. Although the letters include a QR code linking to the 'helping you decide leaflet, this leaflet is not widely available in different language options as of September 2024. This presents a barrier for individuals with limited English proficiency if their language option is not available, potentially impacting informed decision-making and access to services.

Data Sharing/IT: The service only becomes aware of a client's preferred spoken language or learning disability if this is shared by their GP. Due to a lack of system integration, information cannot be accessed or shared easily, leading to manual workarounds and potential conflicts in priorities.

Key Stakeholders

•Dr Onyeka Erobu, Act on Cancer Together – Provided an insight report identifying barriers and facilitators to breast screening uptake among racially minoritised women in Brighton & Hove, and supplied inclusive images for use in communication materials.

•Shilpa Patel, GP Partner and Prescribing Pharmacist at WellBN Practice – Shared data that enabled the service to re-invite clients using leaflets in their preferred main spoken language.

•Claire Hines, Senior Community Development Worker, The Hangleton & Knoll Project – Continues to support the project by identifying barriers and informing targeted approaches to improve screening uptake.

•Kerrie Simpkins (Cancer Care Coordinator) & Charlotte Walker, Voluntary Action Arun & Chichester – Provided local data and led community events targeting Eastern European populations in areas with low screening uptake.

•ICS, Public Health colleagues, NHS England, and the commissioning lead – Ongoing collaboration and strategic support.

Achievements

•Multilingual Information Access

As of May 2025, the "Your Guide to NHS Breast Screening" leaflet is now available in 30 languages in HTML format, replacing the previous 12-language PDFs. In September 2024, the Service raised the urgent need for additional translations with NHS England (Screening and Immunisation and Quality Assurance teams). This led to a prompt release of the Bengali version, with confirmation that more translations are in progress.

•Community Engagement

Over the past 12 months, the service has participated in several community events. Two of these were held in areas with high ethnic diversity. The Service is also scheduled to attend the upcoming Gunjar Hindu Union event in Crawley, further strengthening our local engagement.

•Targeted Re-invitations with Language Support

Using data provided by WellBN practice, the Service identified clients from ethnic minority groups whose main spoken language is not English. These clients were re-invited for screening and interpreter support was arranged. This approach led to a small increase in uptake with the data received. However, due to the wide geographic coverage of the service, the Service focused on small data sets and recognise that further work is needed to address ongoing barriers.

Next steps

•The West Sussex Breast Screening Service is actively supporting and contributing to NHS England's digital transformation programme for screening services.

•Continued engagement with re-invited clients, working collaboratively with stakeholders to review and address barriers to breast screening attendance.

•Exploring the inclusion of direct links to translated HTML versions of the "Your Guide to NHS Breast Screening" leaflet in 2-day text reminders—bypassing QR codes to improve accessibility and ease of use.

References

1. Uncovering and addressing ethnic inequities in breast cancer diagnosis | Breast Cancer Now
2. New study to investigate breast cancer in ethnic minority groups
3. *Act on Cancer Together Insight report September 2024*
4. bcn_report_blueprint.pdf *(Breast Cancer Now report - references within PDF)*

Tackling challenges of low health literacy in people with Chronic Obstructive Pulmonary Disease (COPD)

*Stefanie Harding, **Specialist** Respiratory Physiotherapist and PhD student, UHSussex – Worthing Hospital*

Background

In the UK, the average reading age of working-age adults is between 9 and 11 years [1]. Approximately 43% (7.1 million people) struggle with everyday health information due to low health literacy levels, which affects their health and costs the economy £3 to £5 billion per year [1]. For individuals with Chronic Obstructive Pulmonary Disease (COPD), low health literacy worsens health outcomes and increases the risk of hospital admission [2,3]. COPD is the third leading cause of death worldwide [4] and a substantial reason for hospital admissions [5].

People with COPD face significant pressure to manage symptoms such as breathlessness, chest clearance, and physical activity independently to avoid worsening of their condition or hospitalisation [4]. How can we expect individuals with COPD to effectively manage their condition if they struggle to understand the health information provided?

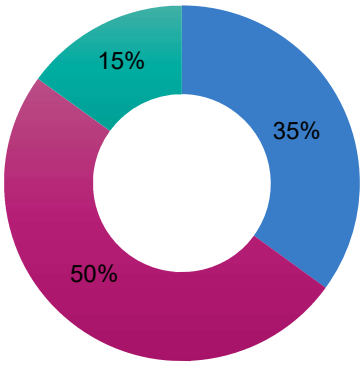
Aim of this project

Raise health literacy awareness among healthcare professionals through collaboration (with individuals with lived experiences, health education teams, multi-disciplinary teams, and NHS trusts via the Health Literacy Forum UK) and teaching

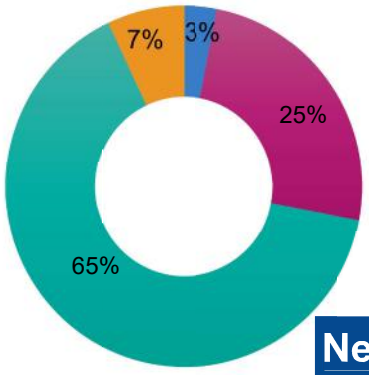
- Enhance communication
- Making health information more accessible
- Empowering individuals to adopt healthier behaviours
- Improving health outcomes and reducing healthcare costs

Results of the Audit on Health Literacy Teaching

Before teaching



After teaching



- Very limited knowledge and not confident at all
- A reasonable amount of knowledge, but not that confident
- A good amount of knowledge and fairly confident
- Extensive knowledge and very confident

Impact

Personal development:

- Gained skills and knowledge to apply an "equity lens" to improve population health.

Expanded professional networks:

- By connecting with other fellows, linking with mentors and other collaborators.

Healthcare professional and population impact:

- Increased awareness regarding the importance of health literacy.
- Healthcare professionals demonstrate a readiness to tailor their communication methods, including verbal and written health materials, to better meet people's needs.
- Colleagues revised patient information leaflets and clinic letters to enhance clarity and understanding, making health information more accessible for people with COPD.

Next Steps: What actions can Healthcare Professionals and Educators take?

- Keep raising awareness
  - Create a teaching video for staff
  - Sustain and increase collaboration locally and nationally
  - Including people with lived experiences