



Shaping Our Future

Wellbeing

Transforming lives of those impacted by Rare Diseases: Developing a digital Holistic Centre to reduce reliance on health and social care services and the climate impact of traditional NHS Services.

Zoe Morrison (RGN) SWAN CNS

Rhiannon Edwards (RGN) Rare Diseases Implementation Network

Kirsty Robathan-Smith DDTIV Innovation lead



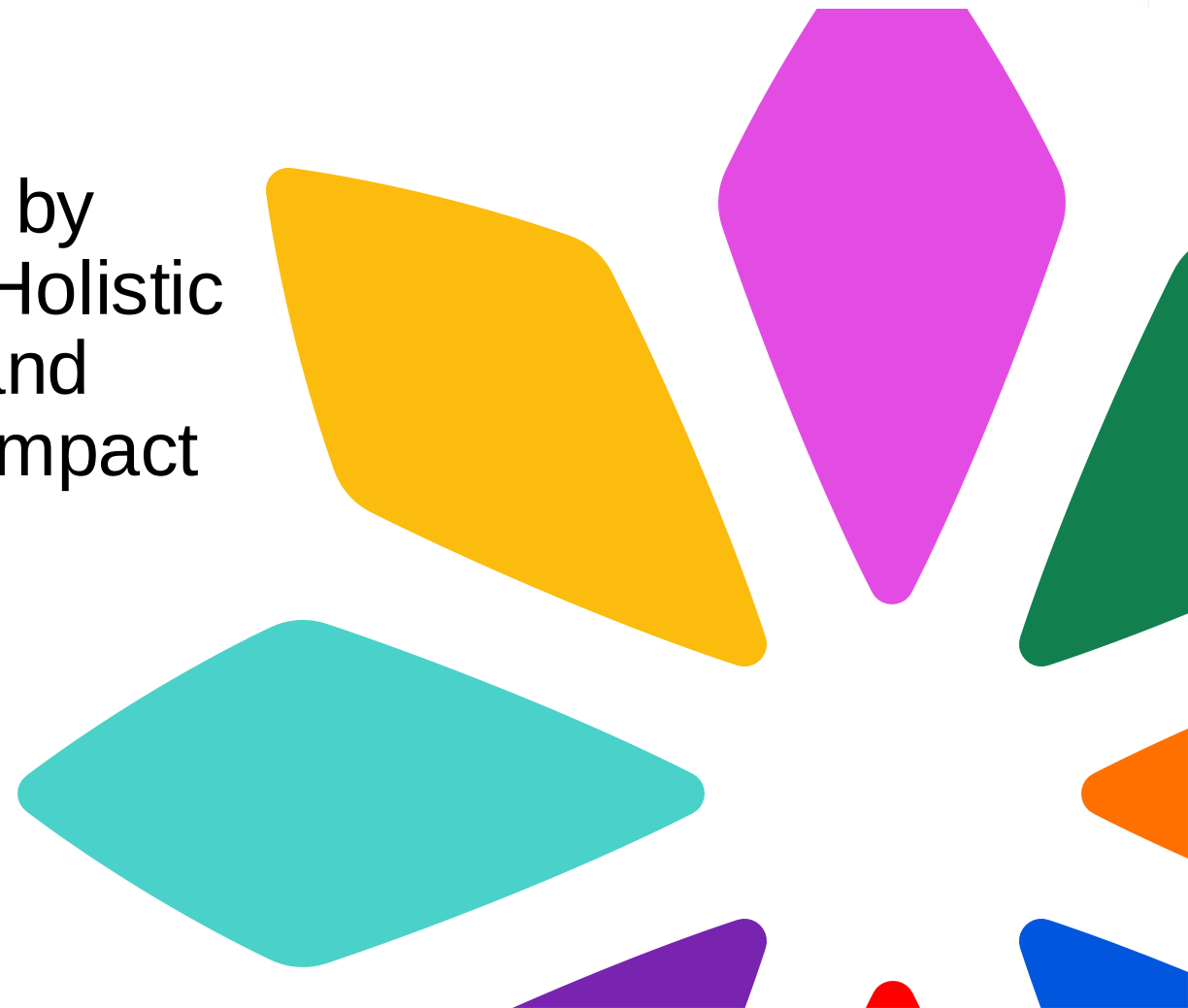
GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board



GIG
CYMRU
NHS
WALES

Rhwydwaith Gweithredu
Clefydau Prin
Rare Diseases
Implementation Network





Shaping Our Future
Wellbeing



GIG
CYMRU
NHS
WALES

Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Problem Statement

People affected by rare and undiagnosed diseases endure medical, emotional, psychological and social distress. Impacting on poor life experience and increased use of primary care, unplanned and emergency care to manage their conditions.

Aim Statement

By September 2025, we will have proven our concept of a one point of access digital Rare Care Centre for Wales, by achieving improved well-being with 70 individuals impacted by rare and undiagnosed diseases (and the potential of reducing healthcare utilisation). Resulting in a saving of 143,000 metric tonne of carbon in NHS Wales, and implementation of the Healthier Wales policy.





Shaping Our Future
Wellbeing

Data from Syndrome Without A Name (SWAN) Clinic

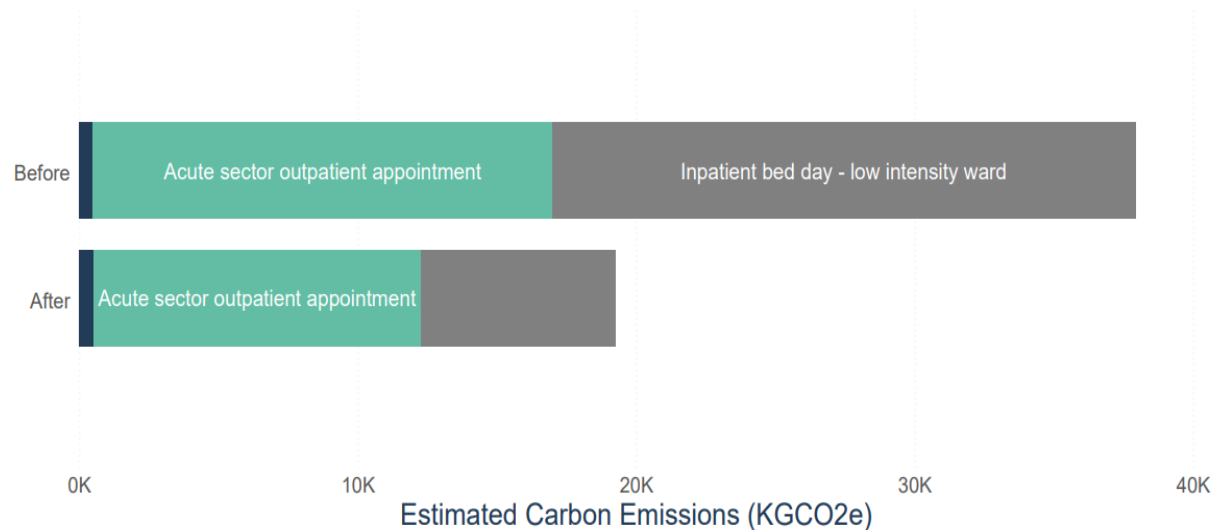


GIG
CYMRU
NHS
WALES

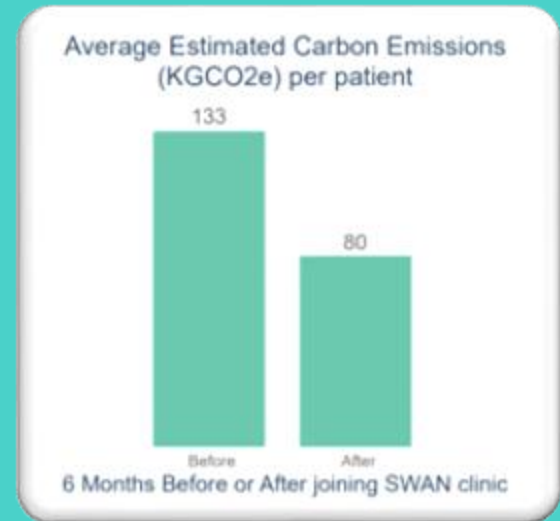
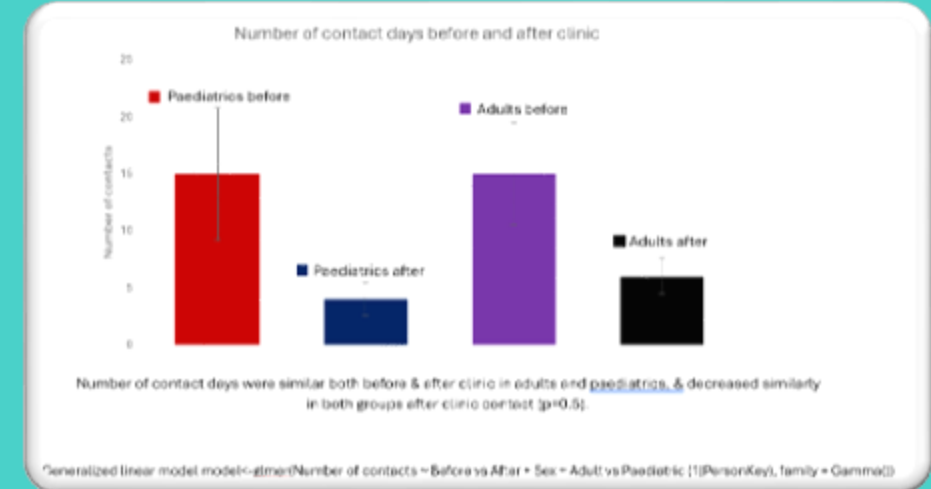
Bwrdd Iechyd Prifysgol
Caerdydd a'r Fro
Cardiff and Vale
University Health Board

Total Estimated Carbon Emissions (KGCO₂e) by Contact Type

Healthcare Unit • A&E visit • Acute sector outpatient appointment • Inpatient bed day - low intensity ward



As shown in the breakdown of contact types, this decrease in carbon emissions was likely driven by the decrease in inpatient stays among the SWAN Clinic patients. When looking at total carbon emissions for the cohort, there was an estimated **49%** decrease between the 6 months before and after attending the SWAN clinic.

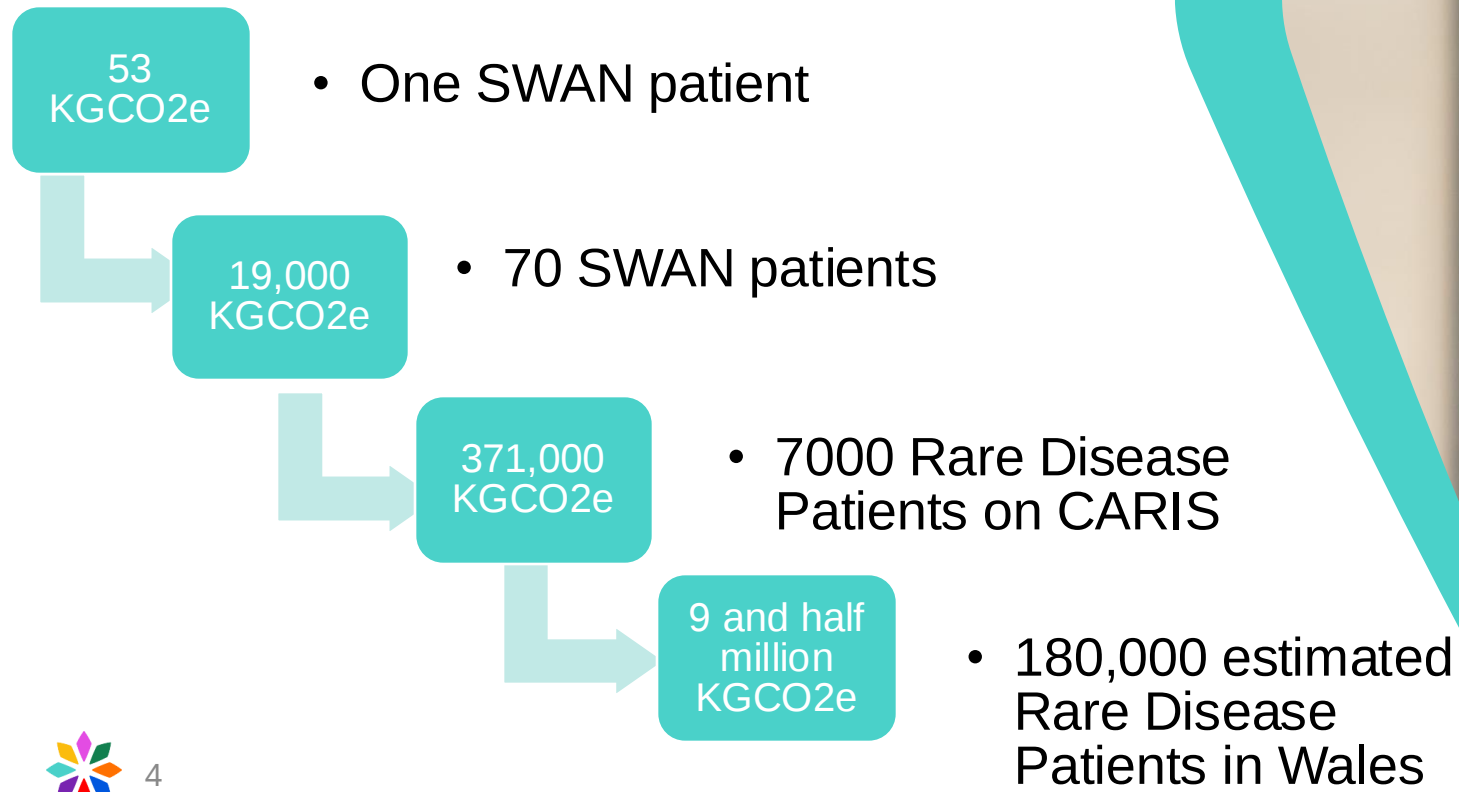




Shaping Our Future

Wellbeing

In six months, the impact offering support online via the Wales Digital Rare Care Centre could have on reducing the carbon footprint of NHS services.



Barriers

Enablers

Achievements

Risk Adverse organisation

Lack of resource allocation

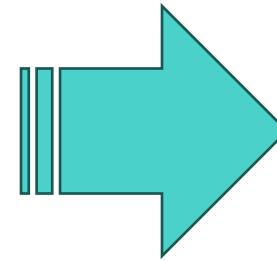
Lack of strategic priority

Service user/clinical led

Free Digital Platform

Alternative lens of impact

Transformation Champion

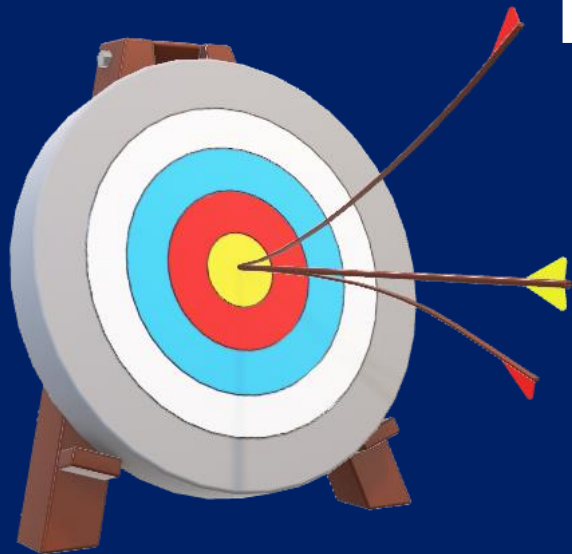


- 🐎 Collaboration
- 🐎 A joint vision
- 🐎 Philanthropic support from Carecircle
- 🐎 Different lens of impact
- 🐎 The Wales Rare Care centre has been recently discussed as an exemplar at the **DAVOS** and **HIMMS** conferences.
- 🐎 Transformation of Rare Disease service provision that can be scaled up to a once for Wales, and global answer to clinical and service user needs.



Shaping Our Future
Wellbeing

What we need to progress



Bravery

Trust

Support



davos wjcc
wales_rare_care_centre
estonia england
carecircle bevan_commission
cf_europe abuhb swan
rareminds himms cvuhb dragons_heart_academy
genomics_england m4rd western_australia
swan_cymru northern_ireland life_science_hub
rdin welsh_government uk_rare_disease_nursing_network hcrw npgg
sounding_board scotland gpw ambrose

Collaborations

