

A demographic profile of participants recruited to research studies in CTM UHB between April 2023 and March 2024



Authors: Dr Megan Elliott, Catrin Vaughan, Rhian Beynon & Prof John Geen

Cwm Taf Morgannwg University Health Board, Research & Development Department. Contact: Megan.Elliott@wales.nhs.uk

BACKGROUND

- Cwm Taf Morgannwg (CTM) University Health Board (UHB) serves a population of 444,037 people [1]. The area has high rates of **deprivation** and **lower life expectancy** than the Wales average.
- Participating in research offers NHS patients opportunities [2] to:
 - Access **new treatments** and interventions
 - Improve treatment and **quality of life**
 - Contribute to science**
 - Play an **active role** in their own health and care
- People should have **equal** opportunities to participate in, and engage with, research and **equitable** access to clinical trials [3].
- '**Equality, diversity and inclusion**' is a cross-cutting theme in the Health and Care Research Wales Research Matters plan [3] and the CTMUHB R&D strategy.
- Researchers in England have found **disparities** between disease prevalence, ethnicity, geographical location and recruitment into research [4,5].
- This raises concerns that research studies are not recruiting from populations with the **greatest need**, nor recruiting a sample that is **representative** of the general / local population.

Supports the development and delivery of high-quality collaborative research across the Health Board and ensures it is conducted and managed to a high scientific and ethical standard.

Receives funding from Health and Care Research Wales, CTMUHB, Grants, Charities and Commercial sources to build capacity & capability, to optimise access, benefits and impact.



CTM UHB R&D Department

In the financial year 2023 – 2024, CTM R&D had:



- Supports with:**
- Governance and Study set-up
 - Identifying funding opportunities
 - Study delivery
 - Strengthening partnerships and collaboration
 - Mentoring Research across the UHB

The CTM R&D Strategy 2025-30 highlights our commitment to Equality, Diversity and Inclusion (EDI), including a strategic objective focused on identifying and targeting under-represented population groups.

CHALLENGE

Despite a high level of research activity within CTM UHB, we do not currently have **evidence-based insight** of the **demographic characteristics** of participants recruited to research studies, and an indication of whether recruits are **representative** of the local population.

AIM

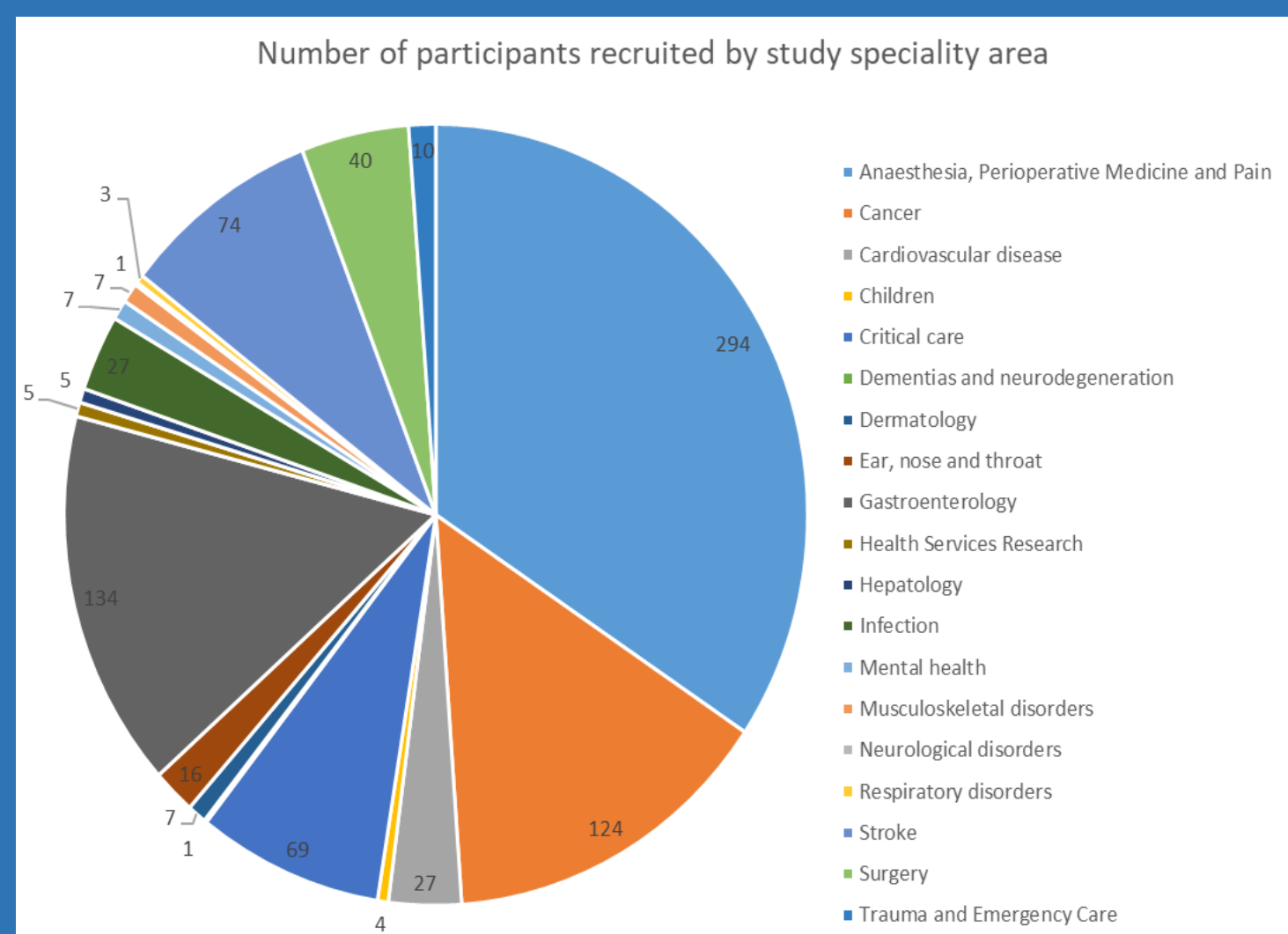
To develop a **baseline demographic and socio-economic profile** of the participants recruited to research studies delivered in CTM UHB in a single financial year.

METHODS

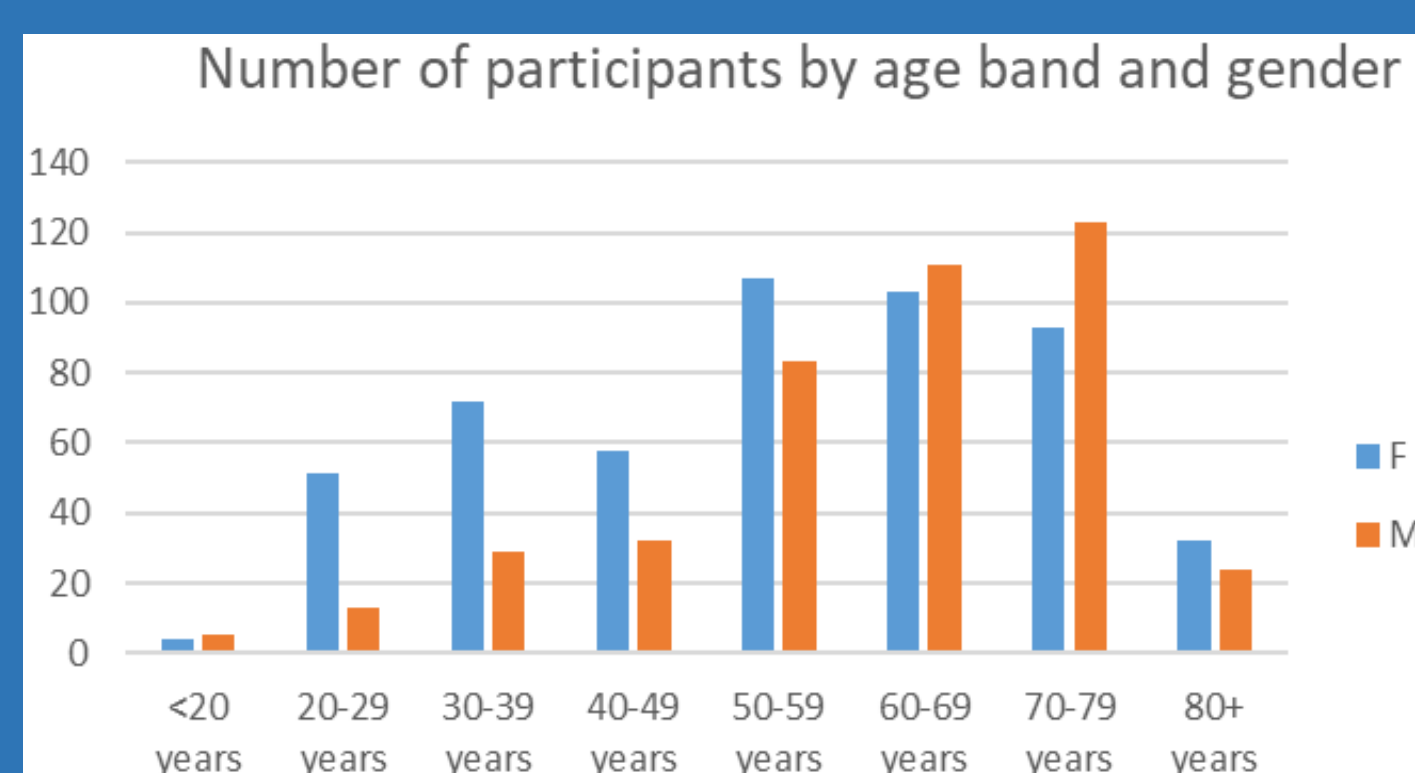
- NHS/hospital numbers for participants recruited to any R&D Delivery supported non-commercial research study in CTM UHB between 01.04.23-31.03.24.
- Dataset created to collate postcode, gender & age for all recruits. Information about study type and speciality recorded.
- Descriptive statistics to develop the profile. Deprivation quintiles compared to CTM quintile data (2019) [6]. QGIS software used to develop map of recruit distribution.
- The project was registered as a service evaluation with R&D and had IG approval

FINDINGS

The dataset included 47 R&D Delivery supported studies (23 interventional, 23 observational and 1 both), covering 20 speciality areas, which recruited a total of 941 participants between 01.04.23-31.03.24.



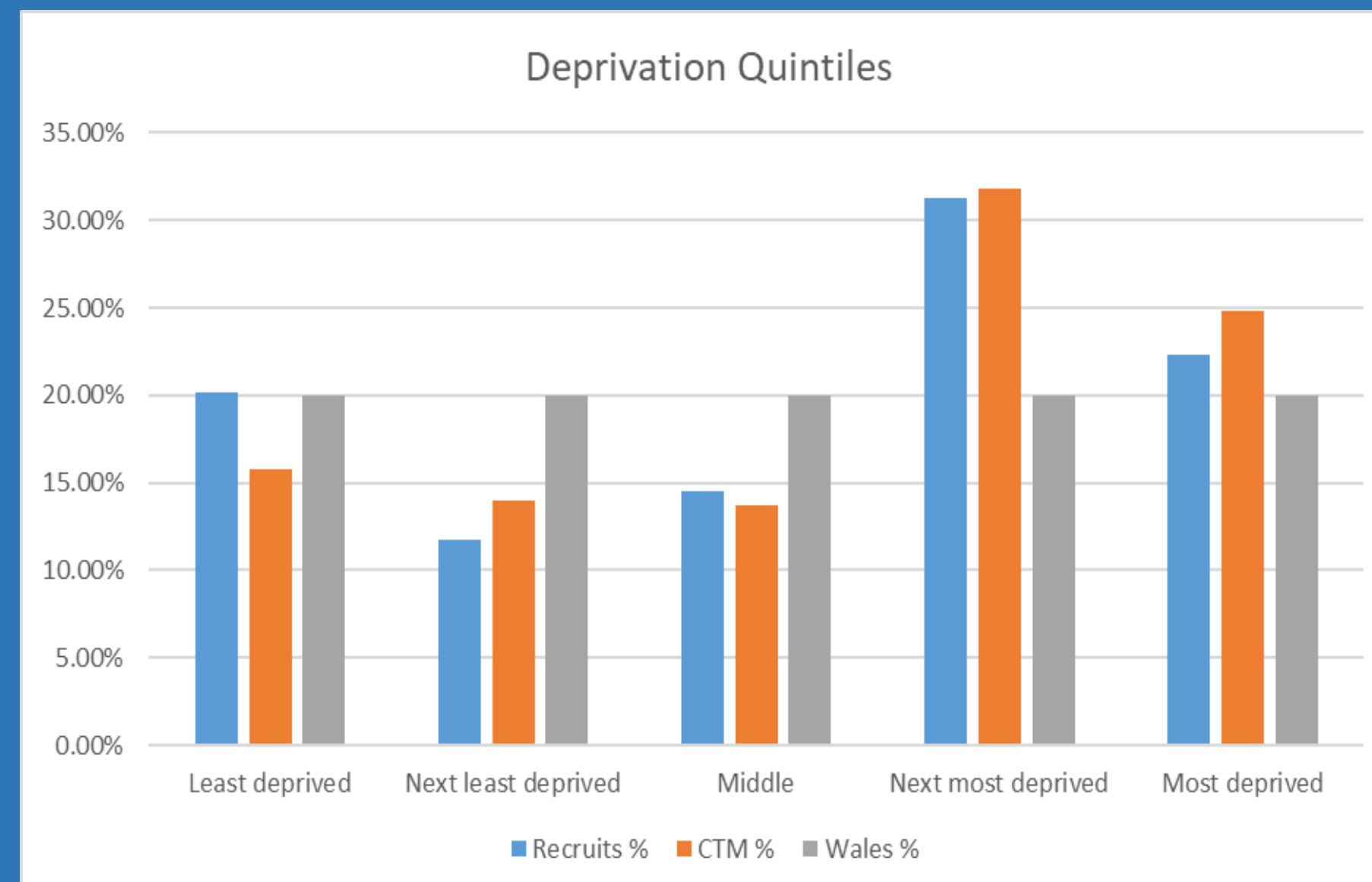
More females (55.3%, n=520) were recruited to studies than males (44.7%, n=420).



However, when participants recruited to 'Reproductive health and childbirth' studies are removed (n=86), recruitment is evenly split between females (50.7%, n=432) and males (49.3%, n=420).

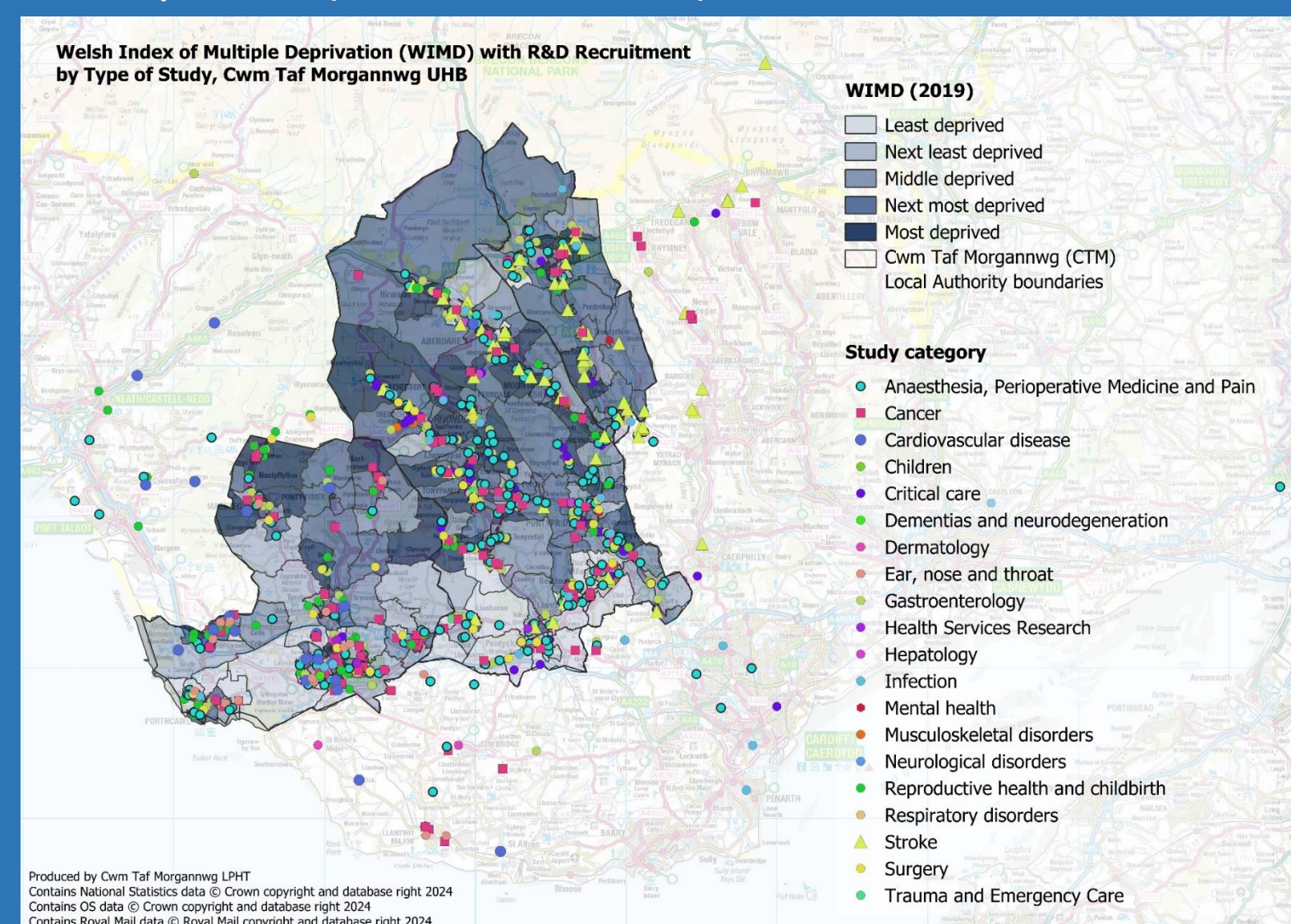
Ethnicity data was available for 9 participants (0.01%).

Deprivation is the lack of access to opportunities and resources, which we might expect in our society. The Welsh Index of Multiple Deprivation (WIMD) is the Welsh Government measure of relative deprivation for small areas in Wales [7]. Deprivation quintile was available for 937 participants (99.6%).



Recruited participants were spread across the five WIMD quintiles; ranging from: least deprived (n=189, 20.2%), next least deprived (n=110, 11.7%), middle (n=136, 14.5%), next most deprived (n=293, 31.27%) and most deprived (n=209, 22.31%).

In CTM UHB (as of 2019), 56.6% of residents lived in the two most deprived quintiles. Comparably, 53.4% of recruited participants lived in the two most deprived quintiles.



DISCUSSION

- Generally participants recruited to studies within CTM between 2023-24 are **representative** of the CTM population in terms of deprivation quintile.
- Participants living in the most deprived areas were slightly under-represented, and those in the least deprived areas were slightly over-represented, but the differences are small.
- A **strength** of this study is that socio-economic data is based on participant home postcode, rather than address of recruitment site, as other studies have used [4,5].
- A **limitation** of this study is that ethnicity data was poorly coded and only available for 0.04% of the participants recruited. Furthermore, it was not possible to access data regarding participant health condition or disability status.
- Data was unavailable for 7 studies due to; opportunistic recruitment (n=1), staff participants (n=3), recruitment by central study team (n=2) and NHS/hospital number not collected (n=1).
- Data was only available for studies supported by the R&D Delivery team. As a consequence, the dataset does not include participants recruited to some studies in primary care.
- Future research** should build on the findings presented here to explore representativeness of participants recruited to studies across Wales and over a longer time period. Further exploration of participant health conditions would provide additional insight about inclusivity of research opportunities.
- The R&D department is exploring ways to ensure research is accessible to all, with research already being undertaken and explored with groups such as the gypsy/traveller community and prison population and families.
- Next steps include:
 - An R&D evaluation of the barriers and facilitators to participating in research as reported by individuals invited to participate in research in CTM.
 - Working with the Information and R&D delivery teams to explore recording additional data (e.g. ethnicity, health status) routinely.

References: [1] Stats Wales, 2024. Population estimates by local health boards and age. Available at: <https://stats.wales.gov.wales/Catalogue/Population-and-Migration/Population/Estimates/Local-Health-Boards/populationestimates-by-lhb-age>. [2] NIHR, 2023. Why taking part matters. Available at: <https://bepartofresearch.nihr.ac.uk/take-part-in-research/why-taking-part-matters/>. [3] Health & Care Research Wales, 2022. Research matters: our plan for improving health and care research in Wales 2022-2025. [4] Bower, P., Grigoroglou, C., Anselmi, L., Kontopantelis, E., Sutton, M., Ashworth, M., Evans, P., Lock, S., Smye, S. and Abel, K., 2020. Is health research undertaken where the burden of disease is greatest? Observational study of geographical inequalities in recruitment to research in England 2013-2018. *BMC medicine*, 18, pp.1-11. [5] Abel, K.M., Radojic, M.R., Rayner, A., Butt, R., Whelan, P., Parr, I., Gledhill, L.F., Minchin, A., Bower, P. and Hope, H., 2023. Representativeness in health research studies: an audit of Greater Manchester Clinical Research Network studies between 2016 and 2021. *BMC medicine*, 21(1), p.471. [6] Stats Wales, 2019. WIMD 2019 Local Health Board Analysis. Available at: <https://stats.wales.gov.wales/Catalogue/Community-Safety-and-Social-Inclusion/Welsh-Index-of-Multiple-Deprivation/WIMD-2019/localhealthboardanalysis>

Acknowledgments: Many thanks to all the CTM Research & Development Delivery team for supporting data collation from study spreadsheets, Louise Carver (CTM Information Systems) for supporting with data provision and Ciarán Slyne and Stella Liapi (CTM Local Public Health Team) for analysis and mapping support.