University Hospital Southampton
NHS Foundation Trust

Wessex SDE Equalities Impact Assessment Policy, V1

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Description	This policy informs how the Wessex SDE will protect patient and public privacy		
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1 Version control

Date	Author(s)	Version created	Approval committee	Date of approval	Date next review due	Key changes made to document
8/8/25	Mark Heffernan PPIE SDE Team	1	Chris Kipps Mikayala King Rachel Chappell James Batchelor	Florence	6/8/26	First Version

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3 Introduction

The Wessex SDE is an NHS-owned research data platform that securely holds and links NHS patient data for approved research and innovation. It aims to improve health outcomes by enabling research in a controlled environment that safeguards patient privacy while maximising public benefit. Key objectives include:

- **Protecting Data:** Provide a secure, cloud-based computing environment where sensitive health data are accessed only by authorised researchers for approved projects. No identifiable data leaves the environment and access is time-limited.

- **Enabling Research and Innovation:** Accelerate health research, service planning and “learning health system” improvements by facilitating efficient data access to high-quality linked datasets in Wessex.

- **Ensuring NHS Control and Benefit:** Operate under NHS oversight (via UHS as Host Organisation) so that data use aligns with NHS values and public benefit, not commercial exploitation.

- **Public Trust and Transparency:** Earn public trust through robust governance, transparency in decisions, and demonstration of clear benefits to patients and communities.

These aims align with national NHS ambitions. NHS England’s strategy for the NHS Research SDE Network emphasises that SDEs must remain under NHS control, involve patients and public in governance, and deliver public benefit. Equality, diversity, and inclusion considerations are integral to these aims; the SDE should improve health for all and not exacerbate disparities.

This policy may be amended from time-to-time, and you can obtain a current version at WessexSDE.nhs.uk

4 Scope and purpose

This policy sets out the commitment of University Hospital Southampton NHS Foundation Trust, as the lead organisation for the Wessex Secure Data Environment (SDE), to proactively identify and mitigate risks of discrimination, exclusion, or inequality arising from the design, delivery, or use of the SDE.

The purpose of this policy is to ensure that Equality Impact Assessments (EqIAs) are systematically applied to all key decisions, policies, processes, and data projects within the Wessex SDE. This supports compliance with the Public Sector Equality Duty (PSED) under the Equality Act 2010, and reinforces our organisational values of fairness, transparency, and accountability.

This policy applies to:

- All SDE-related programmes, policies, procedures, and digital infrastructure;
- Governance mechanisms (e.g. the Data Access Committee);
- Public involvement and engagement activities;
- Research and data access approvals;
- Communications, workforce involvement, and external collaborations.

Through this policy, we aim to:

- Identify and address any disproportionate or unintended impacts on people with protected characteristics;
- Embed equality considerations into the fabric of secure, ethical data use;
- Demonstrate a transparent, inclusive approach to data governance that earns and maintains public trust.

The Privacy Policy sets out how University Hospital Southampton (UHS), as the lead organisation delivering the Wessex Secure Data Environment (SDE), collects, stores, uses, shares, and protects personal and health-related data processed through the SDE platform. It is designed to:

- Inform data subjects (e.g. patients, public, researchers) about what data is held and why.
- Demonstrate compliance with UK GDPR, the Data Protection Act 2018, and relevant health data laws.
- Build and maintain public trust and transparency in the secure use of health and care data for research and service improvement.

All staff and partners involved in the Wessex SDE are expected to be familiar with and adhere to the commitments made in this policy. By following these requirements, the Wessex SDE programme will continue to foster trust, meet its legal obligations, and exemplify best practice in privacy for the benefit of patients, participants, and the public.

4.1 Legal and Policy Framework

The Wessex SDE's approach to equality impact assessment is grounded in both statutory obligations and NHS policy requirements. This framework ensures that the SDE is designed, governed, and delivered in a way that actively identifies and mitigates potential discrimination or disadvantage.

Equality Act 2010 – Public Sector Equality Duty (PSED)

Under Section 149 of the Equality Act 2010, public bodies—including University Hospital Southampton as the host of the Wessex SDE—are legally required to:

- Eliminate unlawful discrimination
- Advance equality of opportunity
- Foster good relations between people who share a protected characteristic and those who do not

UK GDPR and Data Protection Act 2018

The processing of health and personal data for research or service planning must be fair, transparent, and non-discriminatory. Specifically:

- Article 5 of the UK GDPR requires fairness and accountability in data use
- Article 9 requires safeguarding of special category data, including health and racial/ethnic data
- Equality considerations must be embedded in Data Protection Impact Assessments (DPIAs) where relevant

NHS England SDE Governance and Transparency Framework

NHS England requires all Secure Data Environments to:
Promote equity and transparency in public data use
Involve seldom heard groups in decision-making and PPIE activity
Publish key governance documents, including EqIAs where relevant

This is reinforced through the NHS Constitution, which commits to non-discrimination and accessibility in NHS services

National Data Guardian (NDG) and Caldicott Principles

The NDG's principles, particularly around justifying the purpose of data use, minimum necessary access, and accountability, require that equality considerations are addressed alongside privacy.

This supports the use of EqIAs as part of:

- Governance reviews
- Access approval workflows
- Stakeholder engagement planning

This policy should be read and applied in conjunction with these laws and guidelines, ensuring legal and regulatory compliance in all transparency and disclosure practices.

5 Definitions

Term	Definition
Caldicott Guardian	A senior person within a health or social care organisation who makes sure that the personal information about those who use its services is used legally, ethically, and appropriately, and that confidentiality is maintained
Caldicott Principles	Are eight guiding rules used across the NHS and social care to make sure that people's confidential health information is handled with respect and care.
Data Controller	Is the organisation (or sometimes individual) that decides why and how personal data is collected and used. In the NHS, this means the Trust, GP practice, or other body that determines the purposes and means of processing patient information, and is legally responsible for complying with data protection law.
Data Protection Act 2018	Is the UK's main data protection law. It sets out how personal information must be collected, used, and stored safely, and incorporates the rules of the UK GDPR to protect people's privacy and rights.
National Data Guardian	Is an independent authority that advises and challenges the health and care system on how people's confidential information is used. The NDG's role is to make sure data is handled securely, lawfully, and with respect for patients' rights and expectations.
NHS England's Secure Data Environment (SDE) Governance Framework	It sets the rules and standards for how SDEs operate. It ensures that health data used for research and analysis is accessed safely, transparently, and in ways that protect patient privacy and maintain public trust.
NHS Records Management Code of Practice 2021	Is a set of guidelines on how NHS organisations should create, use, store, and dispose of records. It ensures that information is managed securely, kept only as long as needed, and handled in line with legal and professional standards.
Personal data	Any information, which directly or indirectly can identify an individual such as name, identification number or contact details
Pseudonymisation	The processing of personal data in a way that it cannot be attributed to a specific data subject without the use of additional information, provided that additional information is kept separate
UK GDPR	Is the retained version of the General Data Protection Regulation ((EU) 2016/679) as it forms part of the law of England and Wales
Wessex SDE	The Wessex Secure Data Environment (or SDE) is a secure, NHS-owned and run platform that stores and links patient data for research and analysis. It is built to the highest standards for privacy and security of NHS health and social care data.

6 Details of policy

6.1 Stakeholder Engagement and Consultation

6.1.1 Stakeholders Affected

The Wessex SDE's policies and operations affect a broad range of groups. For example, some of groups may potentially be impacted as individual data subjects, or because of how their demographics or protected characteristics (or those of the groups they work with) are represented within datasets held by the SDE (e.g. the potential for bias). Others are potentially impacted as users or potential users of the SDE (e.g. some individuals or groups may not be able to access the services offered as easily as others).

- **Patients and Public:** All residents whose health data may be included in the SDE (broadly across Dorset, Hampshire, Isle of Wight). This includes protected characteristic groups (e.g. different ages, ethnicities, etc.) and underserved populations. Public trust and a clear public mandate are considered essential to the effective operation of the Wessex SDE.

- **Researchers and Analysts:** Academics, NHS analysts, and other authorised researchers who will request access to data. Inclusive researcher onboarding is needed so that no group is unfairly barred from using the SDE.

- **NHS and Partner Staff:** UHS as host, Integrated Care Boards (ICBs) in Wessex, and partner organisations involved in governance (Data Access Committee members, SDE operations team, etc.).

- **Wider Community:** Voluntary sector and community groups (especially those representing seldom-heard voices) who have an interest in how health data is used and protected.

6.1.2 Patient & Public Involvement, Engagement and Participation

The Wessex SDE programme has proactively involved stakeholders to shape an inclusive SDE. Engagement activities and findings include:

- **"Listening to Seldom-Heard Groups" (Nov 2023–Apr 2024):** An extensive outreach to *underserved communities* across Wessex. The team visited 40 community, charity, and faith groups, speaking with over **560 people** from seldom-heard populations. Participants included carers, people living with long-term conditions, individuals with histories of substance abuse, people in economic hardship, settled travellers, LGBTQ+, people with English as an additional language, veterans, disabled people, older and young people. This engagement ensured voices of those less likely to be heard by decision-makers were captured. Key themes from the Seldom-Heard Groups (SHG) engagement are summarised in Section 4.

- **Wessex Public Panel on NHS Data (Summer–Autumn 2024):** A deliberative dialogue process with a diverse "Public Panel" of Wessex residents was convened for a multi-day deliberative event. Approximately 50 members of the public, representing a diverse cross-section of Wessex's population, spent four days learning about the SDE, discussing data use scenarios, and co-developing recommendations. Inclusion was central: recruitment ensured the panel reflected local diversity in age, gender, ethnicity, and experience to **foster ownership** and support for the SDE. Over the sessions, the panel examined governance, risks, and values, culminating in recommendations for SDE design, operation and decision-making is robust, trustworthy, and reflects the views of the Wessex Public. The recommendations of the Public Panel have been further tested and supported by a polling exercise conducted by Censuswide in December 2024, comprising 2001 members of the public reflective of the region.

- **Digital Critical Friends & Ongoing PPIEP:** In addition, the SDE team has a standing group of 19 public contributors ("Digital Critical Friends" or DCFs) who have been selected to be a diverse group, reflective of the region's geography and communities. DCFs are actively involved and represented in all aspects of programme governance, ensuring that the views of the Wessex public are considered.

6.1.3 How Engagement Influenced SDE

Engagement feedback has directly informed Wessex SDE policies and highlighted equality considerations. For example, seldom-heard participants stressed the need for impartial, diverse governance and strong privacy safeguards to prevent exacerbating inequalities). In response, the draft Data Access Committee Terms of Reference emphasise diverse membership and transparency (see Section 3).
Similarly, the Public Panel recommended specific measures such as embedding public voices in governance, publishing clear plain-language information, and ensuring fair representation in decision-making. These inputs have shaped SDE governance documents (e.g. adding public members to committees, developing easy-read communications, etc.) and will guide Standard Operating Procedures (SOPs) still in development. The engagement findings on equalities and inclusion are explicitly considered throughout this EqIA.

6.2 Governance Structures and Equity

6.2.4 Governance Overview

The Wessex SDE is governed through a multi-layer framework. Key elements of this framework are:

- A **Wessex SDE Programme Board** (established by UHS) oversees strategic development and reports to an Executive Sponsor Group of regional NHS sponsors.

- A **Wessex Data Access Committee (DAC)** is being established as an independent decision-making body for reviewing data access requests and advising on SDE data use policies. This includes public representatives.

- UHS, as Host Organisation, ensures regulatory compliance and hosts the DAC, while NHS England and regional ICBs provide strategic oversight via a Memorandum of Understanding (MoU).

Wessex Data Access Committee (DAC) and Equitable Access: The Wessex DAC is critical for ensuring fair and equitable access to the SDE's data. According to its Terms of Reference (ToR), the DAC's purpose is to review each data access application and recommend approval only if it meets strict criteria around ethics, public benefit, and privacy. Additionally, all members are tasked with keeping equality considerations in mind when considering any aspect of an application. Key features of the DAC (supporting equality) include:

- **Diverse Membership:** The committee comprises nine (9) voting members and a non-voting chair with diverse expertise and lived experience. This includes three (3) Public Members (lay representatives providing patient/public perspectives) and six (6) Professional Members from clinical, research, data governance, ethics, and law backgrounds. Having nearly one-third lay members ensures voices from the community are present and influential in decisions. A supermajority of 70% of members (rounding up to the nearest whole number) is required to approve a data access request.

- **Public members are reimbursed for involvement to support inclusive participation.** Rewarding and recognising public contribution through payment and reimbursement of expenses, in line with NIHR's public payment policy, the SDE supports members of the public to be involved and contribute lived experience to ensure that their voices are heard in research. The Public Panel specifically recommended that the DAC have a "diverse mix of backgrounds, skills, and experience – including ¼ to ¾ public members" to reflect the community. The Wessex DAC's design aligns with this by targeting robust public representation. Diversity of gender, ethnicity, and expertise has been pursued in member recruitment (an open process overseen by the Wessex SDE Board).

- **Transparent, Criteria-Based Decisions:** The DAC will apply standardised criteria to each request, ensuring decisions are based on merit and alignment with SDE core principles (e.g. scientific value, patient benefit, legal compliance). It will develop a "precedent review pathway" to ensure consistency and guard against bias or case-by-case unfairness. All decisions and their justifications will be recorded and (where possible) published in summary form to promote transparency. This openness helps build trust that access is granted fairly and not influenced by favouritism or irrelevant characteristics.

- **Equity in Access Prioritisation:** If SDE resources are limited (e.g. consultancy time or computing capacity), the DAC is tasked with prioritising data access requests in a fair manner. The criteria for prioritisation will consider public benefit and urgency, rather than the influence or background of the requester; this prevents any one group (e.g. well-resourced institutions) from dominating SDE use at the expense of others.

- **Accountability and Appeals:** The DAC will have an appeals process for any applicants who feel their request was unjustly refused. This will provide a check to ensure decisions can be reviewed for fairness. Additionally, the DAC reports to the Wessex SDE Programme Board and is subject to annual reporting requirements and independent audit of its activities, creating accountability for equitable conduct.

- **Impartiality and Conflict of Interest Management:** Members must declare conflicts of interest; the ToR includes removal of members who undermine integrity or fail to declare conflicts. Public Panel members in the deliberation stressed avoiding staff holding multiple roles (to prevent undue influence) and robust conflict declarations. These safeguards in the DAC structure promote impartial decisions based only on project merits and societal benefit.

- In summary, the Wessex DAC is designed to be an inclusive, representative body that upholds equity in who can access data and what projects are approved. This governance mechanism is a direct mitigator of potential inequality: it ensures decisions are not concentrated in a homogenous group but instead incorporate varied perspectives (including those of patients and underserved groups). The DAC’s role in vetting projects also means it can screen for any research proposals that might negatively impact certain populations, adding another layer of equality oversight at the project approval stage.

In conclusion, the governance structures – particularly the Data Access Committee – are geared towards **equitable access and inclusive oversight**. They set a strong foundation, though some elements (DAC Terms, SOPs) are still being finalised (see Section 5 on next steps). The impact of these structures on equality will need review once fully implemented, but the design intent aligns with best practice and stakeholder expectations for fairness.

6.3 Impact on Protected Characteristic Groups

This section assesses whether the Wessex SDE (its policies for data access, security, researcher onboarding, etc.) could have different impacts on groups protected under the Equality Act 2010, or other underserved groups. It incorporates evidence from the Seldom-Heard Groups engagement and Public Panel deliberation regarding specific concerns or needs of these communities. At this draft stage, most impacts are anticipated impacts (since the SDE is not yet live); they will be validated through ongoing monitoring.

For each protected characteristic, we identify potential risks or benefits and mitigating actions. **Table 1** below summarises the assessment:

Protected Characteristic	Potential Impact and Issues	Mitigations / Actions
Age (younger and older people)	Data research benefits could vary by age group depending on research focus (e.g. studies on older adults vs. youth). Trust in the SDE also varies by age: engagement found younger	**Inclusive Engagement & Communication:** The SDE is committed to continue with tailored outreach to different age groups linked to emerging programme objectives. The SDE’s Seldom Heard

	people were often optimistic about data use, whereas some older people were more sceptical or resigned, feeling their input would not matter. Younger participants voiced anxieties (e.g. about hackers or misuse) but were interested in future benefits, while older participants, especially those with past negative NHS experiences, expressed disillusionment. These attitudes could affect willingness to participate (e.g. opting out of data sharing) and thus impact data representativeness. There is also a risk that overly technical communication might not be accessible to elderly individuals. However, no explicit barriers (e.g. eligibility) exist in the SDE based on age – all patient data (children, adults, elderly) are included under appropriate approvals, and researchers of any age can apply (subject to qualifications).	Groups engagement programme intentionally included older and younger people to capture their needs. Communication materials will be made accessible – e.g. jargon-free summaries and FAQs as recommended by the Public Panel – and distributed via channels that reach older adults (print, community groups) as well as younger audiences (social media). **Trust-building:** Address specific trust concerns by transparently explaining SDE safeguards. For older people feeling "it'll happen regardless," emphasise ongoing opportunities to influence governance (e.g. through public representation on the DAC and future panels). For younger people, highlight data security measures to allay fears. **Research Balance:** The DAC will ensure a mix of projects, including those addressing issues across the life course (from paediatric to geriatric research), so benefits accrue to all age groups.
Disability (including physical, sensory, mental health, and cognitive disabilities)	Disabled individuals have heightened concerns around privacy, discrimination, and whether research will address their needs. Engagement revealed fears that sensitive health information (mental health conditions, HIV status, autism, etc.) could be misused or lead to stigma. Some with disabilities or long-term conditions felt underrepresented in research and worried the SDE might focus on "quick wins" rather than complex issues. If the SDE's data or tools are not accessible (e.g. compatibility with screen readers for blind researchers, or accommodating neurodiverse users), it could disadvantage disabled researchers or staff. Additionally, people with learning disabilities or cognitive impairment may not fully understand data usage or opt-out processes –	**Privacy and Security Protections:** The SDE is designed with strong privacy controls (data pseudonymisation, no export of identifying data) which directly address many disability-related data fears. Emphasise these protections in communications: reassure participants that, for example, insurers or employers cannot access their data, addressing the fear of misuse. **Inclusive Research Agenda:** Through the DAC and stakeholder input, ensure research within the SDE addresses disability-related health issues and does not neglect rare or complex conditions. The public deliberation explicitly considered cases like rare diseases in underserved communities (e.g. sickle cell anaemia) – similarly, the SDE will consider projects on disabilities/mental health as high public benefit, not "low priority." **Accessible Systems and Processes:** Make researcher access

	vulnerable groups “unable to fully understand or opt out” were a concern raised in engagement, indicating the need to safeguard those who cannot easily give informed input.	technology and processes accessible. For example, the user interface of the SDE will be evaluated for compatibility with assistive technologies. Similarly, provide documentation in multiple formats (large print, etc.). When onboarding researchers or DAC members with disabilities, offer reasonable adjustments (flexible meeting formats, assistive software, etc.). **Safeguarding Vulnerable Groups:** Ensure robust governance oversight for data uses involving those who may not consent directly. For example, any inclusion of data from individuals lacking capacity should have ethical safeguards. The DAC and data governance policies will include representation from ethics experts to protect these individuals. **Continued Engagement:** Work with disability advocacy groups (many were included in the SHG outreach) to update SDE policies. For instance, co-develop easy-read explanatory materials for those with learning disabilities about what the SDE means for them.
Sex (Gender)	No direct negative impact is anticipated based on sex – the SDE includes data on all sexes and aims to benefit all. However, historically some research overlooks women’s health or differences between sexes, which is an inequality the SDE should guard against. Women, for example, have been underrepresented in some clinical data, leading to biases in outcomes. There is also a need to ensure both men’s and women’s perspectives are represented in governance and engagement. The SDE’s seldom-heard groups engagement included both men and women (e.g. veterans, carers, etc., included both genders) and did not report gender-specific concerns distinct from other factors.	**Research Inclusivity:** The SDE will encourage and enable analysis by sex where relevant – e.g. researchers should analyse outcomes for men and women to identify any disparities. As part of project approvals, the DAC can prompt researchers to consider whether their study includes participants of all genders and analyse differences (where applicable), echoing national calls for inclusive research design. **Balanced Representation:** In governance and staffing, strive for gender balance. **No Barriers in Participation:** Ensure meeting times and formats do not unintentionally exclude based on gender roles – for instance, consider that women may have more caregiving duties (see Carers section) and schedule key meetings accordingly. Given no specific concerns were raised by public engagement solely

		on the basis of sex, we assess the impact as neutral if these inclusive practices are maintained.
Gender Reassignment (Transgender and non-binary individuals)	The SDE will inevitably hold data on transgender patients (for instance, medical records may show history of gender transition). It is crucial that data use does not compromise an individual's privacy regarding their trans status – privacy is a key concern for this group as disclosure can lead to harassment or discrimination. A risk to monitor is whether algorithms or analyses could inadvertently "out" transgender individuals (e.g. by linking prior names) or whether trans and non-binary people's health needs might be overlooked if research is not inclusive. So far, engagement did not explicitly highlight trans-specific issues (it is possible some participants were LGBTQ+ but discussions cantered on broader themes like trust, stigma, and inequality). We assume the need to ensure data handling is sensitive to gender identity.	**Data Privacy and Consent:** All SDE data is de-identified for researchers; identifiers (like name, NHS number) are not disclosed. This greatly mitigates the risk of outing someone's transgender status through research. Additionally, any particularly sensitive data fields (e.g. gender markers) will be treated with caution and only provided if necessary for the research question. This should also be subject to robust scrutiny by the Wessex Data Access Committee as a key decision-making body of the SDE. **Confidentiality Policies:** Embed strict rules that no attempts to re-identify or single out individuals (e.g. by matching records that could reveal a change in gender) are tolerated – this would be a breach with legal consequences. Researchers must agree to this in data access agreements. **Inclusive Research Practice:** Encourage research proposals that address transgender health inequalities (if relevant data available) or that include transgender participants, to ensure this group benefits from insights. The EqIA process can be revisited if any project might affect trans people (e.g. analysis of gender-specific data) to ensure appropriate review (possibly via ethics approval). **Staff Training:** Ensure SDE staff and DAC members have had diversity training, including understanding the needs and privacy concerns of trans and non-binary individuals. Use gender-inclusive language in all documentation and participant materials, which sets a tone of respect.
Marriage and Civil Partnership	This characteristic is less directly relevant to data access. Being married or in a civil partnership does not in itself affect how one's data is used in the SDE or ability to access data. No impacts (positive or negative) specific to	**No specific action needed** – **Neutral Impact**. The SDE policies apply equally regardless of marital or partnership status. We will remain mindful if any indirect issue arises (e.g. if communication about data usage needs to consider next-of-kin

	marital status have been identified. Engagement did not raise any issues in this area.	or partner consent in some contexts), but none are apparent at this stage.
Pregnancy and Maternity	**Data Aspect:** Pregnancy / maternity status is a health condition and will be part of the data. Research using SDE data could generate findings that benefit pregnant women (e.g. improved maternity care) – a positive impact if such studies are prioritised. Conversely, if not careful, research might underrepresent pregnant women (as often happens in clinical trials). **Participation Aspect:** Those who are pregnant or new mothers may have less time to engage with SDE opportunities (e.g. responding to consultations or joining governance) due to healthcare and childcare needs. For instance, an eligible public member on the DAC who becomes pregnant might face barriers attending meetings. These are practical participation considerations. The engagement specifically reached out to parents/carers, but pregnancy itself was not singled out.	**Inclusive Research and Data Use:** Encourage research on maternal health using the SDE (e.g. analyses on outcomes for pregnant women) to help advance equality in healthcare. Ensure that such projects get due consideration by DAC as contributing to addressing an under-served research area. **Flexible Involvement:** For governance or engagement activities, offer flexibility to pregnant individuals or new parents – e.g. remote participation options, scheduling around medical appointments or breastfeeding breaks. (Notably, the DAC plans to allow virtual attendance and to reimburse expenses/involvement, which can help include those with young infants.) **Workforce Consideration:** Internally, if SDE staff or committee members take maternity leave, have continuity plans so their perspectives are not lost, and they can re-engage post-leave. Given these measures, we expect no inherent bias against this group.
Race (Ethnicity and Nationality)	There are known health inequalities across ethnic groups, and likewise differences in trust towards data initiatives. Seldom-heard engagement included ethnic minority voices (e.g. groups with English as an Additional Language, Traveller communities), which surfaced concerns about misunderstanding and discrimination. Participants worried the SDE could lead to people being “unfairly targeted” due to health status or demographics– this implicitly includes race, given historical abuses in data/research. Some felt their communities’ needs are often overlooked in research, or data might be used to justify policies that do not benefit minorities. Additionally, language barriers might impede	**Targeted Outreach and Communication:** Provide SDE public information in other languages (as needed for Wessex populations) and partner with community leaders in ethnic minority and migrant communities to explain the SDE. The SDE’s seldom-heard groups engagement approached grassroots orgs via Core20PLUS5 inclusion criteria, which will be continued. One aim is to ensure no specific ethnic group opts out disproportionately; future updates of the EqIA may use metrics (e.g. opt-out by demographic) to detect any such bias.

	understanding of the SDE for those whose first language is not English, risking lower awareness or higher opt-out rates in some ethnic communities. On the researcher side, minority researchers might face barriers in access if the process is not inclusive (though no such barrier is intended).	
Religion or Belief	No direct impacts identified. The SDE does not collect new data; it uses existing health records, which may contain some information on religion (if recorded in healthcare settings). Research could potentially look at health outcomes by religion or belief (rare, but e.g. studies on certain religious communities' health practices). The main consideration is to respect religious sensitivities in engagement (meeting times, dietary considerations, holidays) and in any research communications (e.g. avoid scheduling public events on major religious festivals). Engagement did not note religion-specific feedback.	**Respectful Scheduling and Involvement:** Ensure that key meetings or public events are not scheduled on important religious holidays whenever possible (this was noted as a best practice in similar contexts). Provide prayer space or dietary accommodations if hosting in-person workshops. **Inclusive Governance:** Aim to include members of different faith backgrounds in public involvement to provide diverse perspectives (though selection is ultimately by merit and interest). **Data Use:** If any research output might intersect with religious beliefs (for instance, if studying genetic data in contexts that some faith groups view cautiously), consider additional dialogue with those communities. Currently, no unequal impact is evident, so this is assessed as neutral with standard good practice measures.
Sexual Orientation (LGBTQ+)	As with gender identity, privacy is a key concern. Sexual orientation is not typically recorded in most health datasets (except perhaps sexual health services). Still, data could indirectly reveal it (e.g. participation in an HIV clinic dataset). LGBTQ+ individuals may fear data sharing if they think it could out them or lead to discrimination. There is also a history of certain groups being under-served or stigmatised in healthcare, which could translate into research gaps – an equality issue if not addressed. General themes of stigma and discrimination were raised (for example, HIV was mentioned,	**Data Protection:** Similar to gender reassignment, maintain rigorous de-identification and ensure no unauthorised use of data that could identify someone's orientation. Any project focusing on e.g. HIV or sexual health will be scrutinised by the Wessex DAC to ensure it does not inadvertently harm or single out a community. **Community Engagement:** Liaise with LGBTQ+ community organisations (if not already reached in the SHG exercise) to explain the SDE and listen for any concerns. If concerns about trust or historical misuse of data exist, address them with evidence of SDE safeguards.

	which often overlaps with concerns of stigma toward LGBTQ+ groups). Our Seldom Heard Groups work also specifically noted the potential financial implications in relation to HIV positive results making people uninsurable.	**Research Benefits:** Encourage research that examines and addresses health disparities in LGBTQ+ populations (like higher rates of certain conditions or access issues), thereby turning the SDE into a tool for positive change for this group. **Workplace Inclusion:** Internally, ensure an inclusive culture in the SDE team for staff of all orientations, which indirectly supports better outcomes (a team sensitive to diversity will think to check for issues affecting these groups).
Carers (Including those with caring responsibilities for children or others)	Carers are not a protected category under the Equality Act but are an important group often considered. Carers (who could be of any age or gender) might have limited time to engage with SDE opportunities (similar to the Pregnancy / Maternity considerations). They may also have unique insights, for example, carers of people with dementia or disabilities contributed in the SHG engagement, voicing the importance of safeguarding vulnerable individuals' data, and ensuring research benefits those they care for. No policy in the SDE disadvantages carers per se, but we must ensure their voices are not missed due to time constraints.	**Flexible Engagement:** Schedule public meetings or feedback opportunities at varied times or offer asynchronous options (online surveys, written submissions) so carers who cannot attend live events can still contribute. The SDE's seldom-heard group engagement sessions were often done through existing community groups (a helpful approach to reach busy carers on their schedule), which we will continue. **Support for Participation:** If a carer is appointed to the DAC or other role, accommodate their needs (e.g. allow them to attend virtually if travel is difficult, provide information well in advance so they can arrange respite care). **Recognise Indirect Impact:** Carers often advocate for patients' interests – their perspectives in the SDE governance can highlight potential impacts on, say, those with dementia (who may not speak for themselves).
Other Underserved Groups (Socio-economic status, rural isolation, etc.)	People from deprived socio-economic backgrounds or otherwise disadvantaged groups were a focus of Wessex's engagement (via the Core20PLUS5 approach). These groups might experience digital exclusion, lower health literacy, or greater distrust due to historical marginalisation. The SHG engagement found that those in high-deprivation areas or with past trauma felt the SDE could "worsen health inequalities" if not	**Tackling Health Inequalities as a Core Principle:** The SDE programme has explicitly adopted the principle that "Our work will address health inequalities, not entrench them." This ethos will guide project selection and evaluation. The DAC will give weight to projects that aim to improve outcomes in underserved communities. **Public Benefit Criteria:** When weighing data access requests, one criterion is likely the public benefit

	implemented correctly. For instance, if research mainly benefits well-served populations, the gap widens. Additionally, rural communities or those with limited access to research participation could worry they will not see benefits. No specific geographic or income-based barriers exist in SDE policies, but differences in engagement levels are a concern.	case – projects that help reduce known inequalities (e.g. studying a condition that predominantly affects a deprived group) should be favoured. Conversely, any proposal that might inadvertently *increase* inequality would be scrutinised or declined. **Continued Community Engagement:** Keep seldom-heard groups engaged throughout the SDE lifecycle, not just in design. Their feedback can identify if any aspect of SDE operations is creating barriers. **Accessible Services:** Ensure that applying to use the SDE or interacting with its data does not require resources only affluent institutions have. The SDE should offer user support, and the cost model (if any) for access should not exclude academic or NHS researchers from less-funded areas. Also, communicate success stories back to all communities (for instance, if a research project in the SDE led to an intervention in an area of high deprivation, close the loop by informing that community). **Digital Inclusion:** Although patients do not directly use the SDE, information about it (like opt-out processes or public engagement invites) should reach those with limited internet access. Use offline methods (community meetings, leaflets in clinics in low-income areas) to bridge the gap.

This policy recognises that individuals may experience disadvantage at the intersection of multiple protected characteristics. Intersectionality refers to the way in which different aspects of a person’s identity, such as age, ethnicity, gender, disability, sexual orientation, socio-economic status, and religion or belief, interact and overlap to influence their experiences of inequality, discrimination, or exclusion. Rather than viewing these characteristics in isolation, intersectionality recognises that individuals may face compounded or unique barriers when multiple forms of disadvantage or marginalisation intersect.

Considering intersectionality helps ensure that:

- Engagement approaches are not just inclusive of “one group at a time” (e.g. disabled people), but reflect the real-life complexity of identity (e.g. a disabled person from an ethnic minority background).
- Data use and research outputs are assessed not just for general fairness, but for how they might reinforce or help reduce disparities across overlapping communities.
- Governance and decision-making processes are sensitive to groups who may otherwise remain invisible within single-category assessments.

Therefore, EqIAs undertaken within the Wessex SDE will seek to identify and address these overlapping needs through inclusive design, layered analysis, and meaningful engagement with diverse communities.

6.3.5 Key Findings from Engagement on Equalities:

The above assessment is grounded in what our seldom-heard group participants and Public Panel told us. In summary, trust and transparency are the overarching themes that cut across all groups:

- **Trust:** Many participants said that trust in the NHS and SDE must be earned through actions. Those with positive past experiences (often majority groups) tend to trust and see the SDE's potential benefits, whereas those with negative experiences – frequently marginalised groups – feel sceptical and "powerless." This distrust, rooted in stigma or systemic failings, can be a major barrier to engagement and could lead to higher opt-out rates or public opposition if not addressed.

  The SDE must demonstrate early wins, be honest about risks, and involve communities in oversight to build trust. As one Public Panel insight noted, "Without the trust you don't get everyone involved."
- **Transparency and Communication:** Every group wanted clear information on how their data is used, who is accessing it, and what safeguards exist. Fears of data misuse by third parties (like insurers or commercial entities) were common across various demographics. In response, the SDE is implementing a communications plan to regularly publish easy-to-understand updates (e.g. lay summaries of approved projects, data privacy measures). The Public Panel strongly recommended this measure.

- **Governance and Representation:** Engaged citizens expect that those making decisions (like the Wessex DAC) will reflect the population and protect those who cannot readily protect themselves. Calls for diverse and impartial governance were explicit. Our mitigation via the Wessex DAC composition and public involvement addresses this. The Public Panel's top recommendations included "Embed public voices in design and governance, ensure their choices shape policy & outcomes - and are treated equally to experts," which is exactly the approach we are taking by having lay members with equal say and by consulting the public on key policies.

- **Addressing Fears of Inequity:** Seldom-heard groups worried the SDE, if not done right, could worsen existing inequities – e.g. by focusing research on easy gains, ignoring minority needs, or if data quality issues (like missing data more common in disadvantaged groups) lead to biased findings. We have noted these as risks and are instituting checks: e.g. validating datasets for quality to avoid skewed analyses (another Public Panel idea) and ensuring "Five Safes" controls to prevent any data use that could harm a particular group. We acknowledge these concerns and treat them seriously in implementation.

Overall, **no unlawful discriminatory impacts have been identified** in the Wessex SDE's design intent. Many potential issues are being proactively mitigated through inclusive policies. In fact, the SDE has the opportunity to **advance equality of opportunity** by enabling research on health inequalities and by involving underrepresented communities in data-driven innovation. The next section details actions to ensure these positive outcomes are realised and any residual risks are managed.

6.4 Action Plan: Mitigations and Next Steps

While this EqIA finds the Wessex SDE has been developed with equality in mind, it also flags several areas requiring ongoing attention. Many governance processes (DAC operations, detailed SOPs for data access, researcher onboarding, etc.) are still **in development or early implementation**. Thus, some impacts cannot be fully judged at this stage. We have identified **provisional actions** to address potential equality risks and will update the EqIA as the SDE matures. Key actions and next steps include:

1. **Finalise and Implement Inclusive Governance Policies and Standard Operating Procedures (SOPs)**

   We will finalise and formalise policies and procedures (e.g. precedent review pathway) to ensure they explicitly incorporate equality considerations. For example, the Data Access Request Form includes an assessment of public benefit and potential impact on inequalities, to inform DAC's decision-making.
   We have worked with our DCFs to review the full Wessex SDE policy suite and identify those policies or SOPs that require scrutiny, including addressing equalities issues and prevent unintended bias. The DCFs have prioritised scrutiny based on an assessment of risk and public interest, and these will be incorporated into a Patient & Public Involvement, Engagement and Participation programme to ensure a proportionate level of consultation or co-design input from relevant stakeholders.
   Success Measure: Annual reporting by the SDE will include a clear statement of how the results of the DCF policy review and changes uphold impartiality and diversity.

2. **Training for Decision-Makers**

   All Wessex SDE staff, DAC members, and others with governance roles will receive training on unconscious bias, equality legislation, and inclusive decision-making. This ensures that when evaluating projects or handling data, they are aware of and sensitive to the needs of different groups. (E.g., training scenario: considering if a data request could inadvertently exclude an ethnic group's data due to higher opt-outs, and how to mitigate that).
   Success Measure: 100% of Wessex DAC members complete EDI training before reviewing live projects.

3. **Ongoing SDE Public & Participant Involvement:** We will sustain the engagement momentum. The Seldom-Heard Groups engagement recommendations – including draft values-led principles for the SDE – will be formally adopted into the SDE's governance framework. These principles (e.g. "listen to and involve people from marginalised communities") will guide our culture. We will also publish the outcomes of the Public Panel (once the report is finalised) and issue a response action plan.

   Success Measure: Continue to support an active and diverse group of Digital Critical Friends in all aspects of SDE programme governance, with an annual report on their activities at the end of the 2025-26 NHS financial year.

4. **Wessex DAC to Consider Impact on Target Groups**

   The SDE team will work with the Wessex DAC to ensure that it fully considers the equalities impact of data access requests. This includes requiring applicants to demonstrate that they have undertaken adequate Patient and Public Involvement, Engagement and Participation (PPIEP) with the target or impacted demographics, considering both those directly and indirectly affected by the research. Similarly, the DAC should assess whether research engages with, and benefits underserved groups and whether applicants have taken steps to mitigate potential negative impacts on specific communities.
   Success Measure: Percentage of research applications that include engagement with underserved groups will be monitored annually.

5. **Accessibility and Inclusive Communication**

   Develop a suite of accessible materials: translations, easy-read guides, FAQs, webinars (with captions) to ensure all communities can understand what the SDE is and how data is protected. Based on Public Panel feedback, we will "publish clear, jargon-free summaries" regularly. Also, implement during 2025-26 a dedicated website section on SDE equality, where this EqIA and updates on engagement are available for transparency.
   Success Measure: User feedback on communications (collected via surveys) shows ≥90% of respondents across demographic groups find the information clear and accessible.

6. **Data Monitoring and Audit**

We will collect data to monitor impacts on equality. For example: track the demographic makeup of data access applicants and approved projects; monitor any patterns in opt-outs or complaints by group; and assess whether research outputs are benefiting a range of communities. This will feed into an annual review.
Success Measure: Annual report (first due 12 months after launch) will include a review of equalities impact, key metrics (e.g. no particular group is systematically excluded from data or decision roles), and actions taken if any imbalance is found.

7. **Mitigate Data Bias Risks**

   Recognising the risk that some groups' data may be incomplete or of lower quality (often a source of health inequality in analytics), the SDE team will implement data curation processes. We will work with data providers to improve data completeness for under-recorded populations (e.g. ensure ethnicity is recorded, improve data on persons with disabilities). Additionally, any research using potentially biased datasets will be advised (via DAC conditions) to acknowledge and, if possible, correct for such bias.
   Success Measure: Documentation of data quality checks and improvements; requirement for researchers to address data limitations in their analysis plans.

8. **Ensure Fair Access for Researchers**

   Develop a researcher onboarding process that is straightforward and fair. We will especially reach out to researchers from less-established institutions or those early in career, including those from underrepresented backgrounds in data science, to encourage them to use the SDE. Mentorship or collaboration opportunities could be facilitated so that the SDE does not only benefit well-funded research teams.
   Success Measure: Diversity of first-year SDE research projects (by institution type, researcher demographics if known, research topic population).

9. **Periodic EqIA Review and Update**

   Importantly, we acknowledge this EqIA is provisional. Therefore, we will revisit and fully update this EqIA once the SDE has been operational for a period (e.g. 6 months post-launch) when more evidence is available. In the interim, any significant change in policy or any issue that arises will trigger a focused EqIA addendum. We also welcome external input – for instance, sharing this EqIA with community groups or equality experts for feedback.
   Success Measure: Updated EqIA published within one year of operation, with refined analysis based on actual impacts and any newly identified issues.

10. **Public and patient representation**

    The SDE team has a standing group of 15 public contributors ("Digital Critical Friends" or DCFs) who have been selected to be a diverse group, reflective of the region's geography and communities. DCFs are actively involved and represented in all aspects of programme governance, ensuring that the views of the Wessex public are considered. We will continue to monitor the diversity of this group and how reflective it is of the Wessex demographics through an annual review of the DCF group to identify possible changes and potential recruitment of new DCF members.

Finally, we note areas of **uncertainty that require further assessment**:

11. The exact **impact of DAC decisions** on equality will only be clear after we see real case studies of requests and how they were handled. We will examine if any appeals or complaints suggest bias and consider the steps that could be taken to mitigate it.

12. The **public trust** metric (especially among minorities or seldom-heard groups) will be gauged through a range of activities. If trust remains low in any group despite mitigations, we will need

additional actions (like more intensive community engagement or partnership with local leaders).

13. **Cross-SDE Learning:** We will continue to learn from other NHS SDEs and national bodies. As other SDE regions complete their EqIAs or share lessons on inclusion, we will adopt best practices. The Wessex SDE will stay aligned with the NHS Research SDE Network's collective approach to equality.

6.5 Conclusion

At this stage, the Wessex SDE is expected to have a broadly positive or neutral impact on equality if the above actions are carried out. It has been intentionally designed with input from a wide range of people, including those often left out, which has helped identify issues early. There are no indications of systemic negative impact on any protected group built into the plans; on the contrary, the SDE's mission includes reducing health inequalities by supporting research for underserved populations.

The Wessex SDE has been designed with a strong commitment to fairness, transparency, and inclusivity, ensuring that no group is disadvantaged by its operations. Our ongoing PPIE work demonstrates that the Wessex SDE has proactively engaged with diverse communities, identified potential equality risks, and integrated safeguards into its governance and policies.

Key strengths of the Wessex SDE include its inclusive governance structures, such as public representation on the Wessex Data Access Committee (DAC), its transparent decision-making processes, and its dedicated outreach to seldom-heard groups. These elements build trust and help mitigate concerns around data use, privacy, and equity. Additionally, the Wessex SDE has incorporated feedback from its stakeholders and PPIEP engagement efforts into actionable policies, reinforcing its commitment to serving all communities equitably.

As the Wessex SDE moves into full implementation, ongoing monitoring and evaluation will be crucial to ensuring that its policies and processes effectively uphold equality and prevent unintended disparities. The proposed measures – such as tracking the diversity of research applications, assessing public trust metrics, and regularly updating this EqIA – will be essential in maintaining accountability and responsiveness to emerging challenges.

Ultimately, the Wessex SDE has the potential to be a model of best practice in health data environments, promoting ethical and inclusive research while safeguarding patient privacy. By maintaining a culture of continuous improvement, active public engagement, and data-driven oversight, the Wessex SDE can ensure that its benefits are equitably distributed and that it remains a trusted resource for health innovation across Wessex.

7 Roles and responsibilities

The SDE Director of Operations holds interim responsibility for adhering to the commitments in this EqIA Policy. Once a Head of Governance is appointed to the Wessex SDE the responsibilities will be transitioned to the new post holder.

The SDE SRO is accountable for adherence to the commitments in this EqIA Policy.

8 Equality impact assessment

Equality and diversity are at the heart of Trust values. Throughout the development of the policies we give regard to the need to eliminate discrimination, harassment and victimisation, to advance equality or opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited in under the Equality Act 2010) and those who do not share it.

The Policy & Guidance Team hold all equality impact assessments centrally. These are available upon request from Policy&Guidance@uhs.nhs.uk

9 Document review

All Trust policies will be subject to a specific minimum review period of one year; we do not expect policies to be reviewed more frequently than annually unless changes in legislation occur or new evidence becomes available. The maximum review period for policies is every three years. The author of the policy will decide an appropriate frequency of review between these boundaries.

Where a policy becomes subject to a partial review due to legislative or national guidance, but the majority of the content remains unchanged, the whole document will still need to be taken through the agreed process as described in this policy with highlighted changes.

This Wessex SDE EqIA Policy will be reviewed at least annually or whenever significant changes occur in the SDE programme or relevant legislation) to ensure it remains up-to-date and effective.

10 Process for monitoring compliance

The purpose of monitoring is to provide assurance that the agreed approach is being followed. This ensures that we get things right for patients, use resources well and protect our reputation. Our monitoring will therefore be proportionate, achievable and deal with specifics that can be assessed or measured.

Key aspects of this policy will be monitored:

Element to be monitored	All
Lead (name/job title)	Wessex SDE, Director of Operations / Head of Governance
Tool	Website
Frequency	Monthly
Reporting arrangements	Status report to Board and SLT

Where monitoring identifies deficiencies actions plans will be developed to address them.

11 Appendices

None

12 References

None