SAIL DATABANK

Public Involvement & Engagement Policy

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1	14.04.2020	Creation of policy to evidence PI/E commitments.
1.1	04.08.2021	Annual review and addition of a reference

Purpose of document

This document sets out the underpinning principles and the policy position for Public Involvement & Engagement connected with the work of the Secure Anonymised Information Linkage (SAIL) Databank and associated initiatives dependent on SAIL data. NB: The corresponding Public Involvement & Engagement strategy is set out in a separate document [1]. Owners of particular projects will have their own responsibilities in relation to Public Involvement & Engagement but may wish to make use of the SAIL policy and strategy.

Definitions

SAIL –	Secure Anonymised Information Linkage
PI/E –	Public Involvement & Engagement
UKRI –	UK Research & Innovation
HCRW –	Health & Care Research Wales
INVOLVE –	Funded by the National Institute for Health Research, to support active public involvement in NHS, public health and social care research
DPA –	Data Protection Act 2018
GDPR –	General Data Protection Regulations 2016

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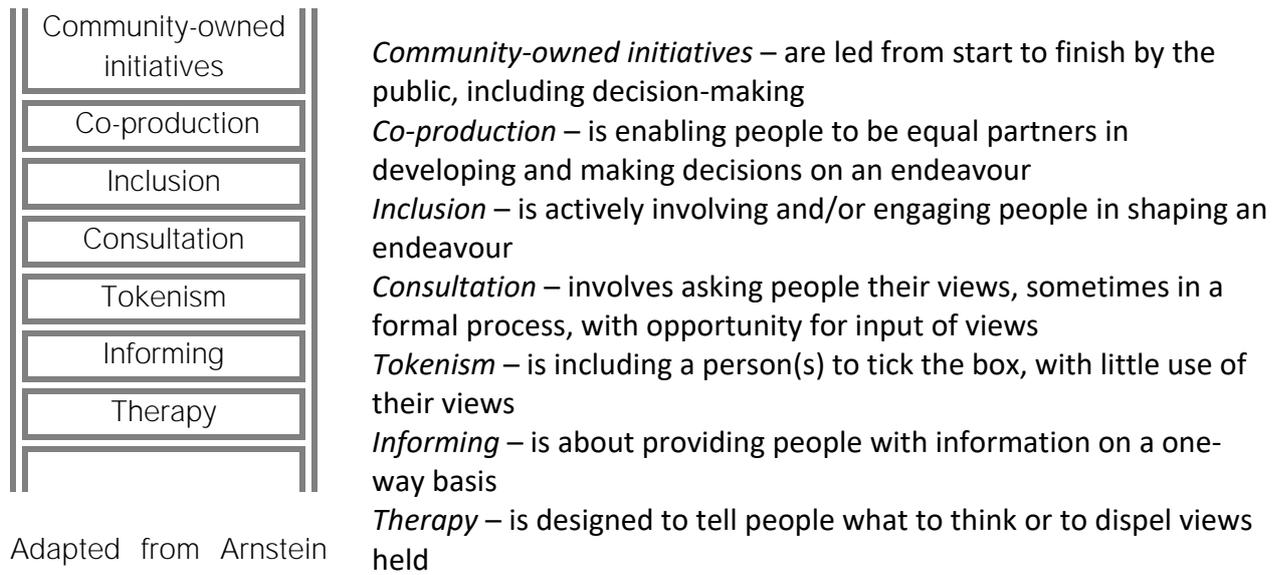**SAIL** DATABANK   National data. Global reach.

Background to the SAIL Databank

The SAIL Databank was established in 2007 by the Population Data Science group at Swansea University (Wales). SAIL was created in recognition of the immense, untapped research potential of individual-level data collected in the course of health and other public service delivery. Its predicate was that making these vast arrays of data accessible safely would open up ways to answer important questions that could not otherwise be addressed without prohibitive effort and cost. SAIL is the bedrock of further Population Data Science investments hosted at Swansea University [2], and the scope of SAIL data has expanded to include administrative data that were not previously accessible (such as education, housing and employment) and emerging health data types (such as genomic, free-text and imaging). In this way, SAIL is an increasingly rich resource for population data science – 'the science of data about people', including wider factors that influence wellbeing [3]. We established a Consumer Panel in 2011 to provide a public voice and gauge social acceptability on the work of SAIL. It remains an essential attribute of SAIL, but also provides public views on the work of associated initiatives [4,5].

Rationale for the Public Involvement & Engagement principles, policy and strategy

We refer to 'Public Involvement & Engagement' as a purposeful set of activities designed to enable an individual or an organisation to work with the public in a two-way arrangement. We primarily focus on the general public, but we include patients, practitioners and other relevant stakeholders within scope. We refer to public involvement as activities in which individuals have a specific role such as being included as co-applicants on research proposals or as members of steering groups for strategic developments. We refer to public engagement as a broader two-way process of listening to, and interacting with, the public about research, particular developments or associated issues in order to take their views on board [6, 7]. Both of these are distinct from communications to disseminate information in a one-way direction only. In this document, we will refer to Public Involvement & Engagement collectively as a single entity covering a spectrum of activities, commonly presented is as a ladder (Figure 1). The original model was developed by Arnstein [8] and it has been adapted many times, as we have done for our model. Other (closely related) terms could have been chosen for the rungs of the ladder; the key message being to show a spectrum of levels of Public Involvement & Engagement.

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Figure 1. Ladder of Public Involvement & Engagement activities

| Community-owned initiatives |
| Co-production |
| Inclusion |
| Consultation |
| Tokenism |
| Informing |
| Therapy |

Adapted from Arnstein [8].

Community-owned initiatives – are led from start to finish by the public, including decision-making

Co-production – is enabling people to be equal partners in developing and making decisions on an endeavour

Inclusion – is actively involving and/or engaging people in shaping an endeavour

Consultation – involves asking people their views, sometimes in a formal process, with opportunity for input of views

Tokenism – is including a person(s) to tick the box, with little use of their views

Informing – is about providing people with information on a one-way basis

Therapy – is designed to tell people what to think or to dispel views held

The perceived importance of Public Involvement & Engagement in public initiatives, such as research and service delivery, has grown increasingly in recent years. This is good practice in a democratic society to demonstrate respect, responsibility and openness towards individuals and society. It has become an imperative for publicly funded initiatives with research councils and charities embodying this in their policies and strategies and signing up to the UK Research and Innovation (UKRI) concordat [9]. Health and Care Research Wales (HCRW) state their commitment to creating an environment in which all the health and social care research that takes place in Wales happens with the public, for the public, so that the people of Wales have a key role in improving the quality and relevance of research [10].

In relation to law in connection with the use of personal data, the EU General Data Protection Regulation 2016 (GDPR) [11] and the UK Data Protection Act 2018 (DPA) [12] make it clear that uses of personal data should be transparent for the exercise of the rights of the data subject. Furthermore, the principles of ethics for science communication recommend proper involvement and engagement with audiences, respecting their views and moving away from the idea of individuals as passive recipients to be educated [13]. Work by organisations such as INVOLVE and Understanding Patient Data (UPD), as well as numerous research studies, have shown people's interest in, and the benefits of, Public Involvement & Engagement [7, 14]. This is important to enable the social responsibilities of those engaging, and those being engaged, to be fulfilled.

Unlike many types of research that naturally come into contact with study participants as part of the activities, research relying only on the use of data can be more remote from the individuals that provided the data. Because of this, there is a need to bridge the communication gap from the most basic to the more complex modes of Public Involvement & Engagement. In recognition of this, an international consensus position has been set out for data-intensive research [15].

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The SAIL Databank and our associated Population Data Science initiatives have an array of funders, partners and collaborators. We seek to conduct our Public Involvement & Engagement in co-operation with all our stakeholders for synergy and the avoidance of duplication. We work with local, national and international networks to share knowledge and expertise as we work towards the common aim of enabling the public voice to be heard and incorporated.

Scope of our Public Involvement & Engagement activities

Our policy position on the scope of our Public Involvement & Engagement activities is based on the ladder diagram shown in figure 1. We endeavour to take a pragmatic approach to Public Involvement & Engagement, to maximise the use of our resources and to work most effectively with the public. We exclude Therapy on the basis that it is not good practice to manipulate the public towards a particular viewpoint. We exclude Community-owned initiatives since ultimately, we are accountable for the work of SAIL. We recognise the key importance of Informing but see this as primarily a one-way mode of communication when its function is static dissemination. However, it is of course, an essential prerequisite of, and integral to, two-way interactions. We acknowledge Tokenism as sometimes being better than nothing, but we discourage it as an approach to Public Involvement & Engagement.

As such, the main two-way categories in scope for our Public Involvement & Engagement activities are: Consultation, Inclusion and Co-production. However, we recognise that the boundaries between the categories cannot always be clearly defined, that a given activity may include several modes of communication and may need to be flexible and change over time. Furthermore, the mode should be chosen to fit the purpose of the activity, be it, for example, advising, shaping, decision-making or reassurance on decisions already made. It can be a challenge to find the optimum balance between informing and eliciting views, and along the continuum of providing a blank sheet to a fait accompli. It is usually needful to begin with some information but without leading or coercing the viewpoints. There is a journey towards awareness and understanding and it is important to work with the public on the way, neither expecting an expert level of knowledge nor assuming a lack of understanding and ability to grasp the issues under discussion. It is important to afford all individuals due respect, and also to encourage everyone to think not only about issues that pertain to themselves, but to include considerations for wider society as part of social responsibility. We acknowledge that, despite our best efforts, we might not be able to achieve full representation of all sectors of the public, or to be certain the views we elicit are a true, stable reflection of public opinion. This is not specific to our work but is a challenge common to achieving meaningful Public Involvement & Engagement since the results will be dependent on complex factors such as personal worldviews, cultural values and recent social or political events and their relative prominence. We seek to take a pragmatic, deliberative approach, prioritising the communication modes that allow maximum public input commensurate with the purpose of the activity.

Principles for Public Involvement & Engagement in the SAIL Databank

This section sets out the principles of Public Involvement & Engagement for the SAIL Databank. Because of the nature of our work, our funding and our location, our principles have been developed mainly from, and accord with, the statements of the UKRI [9] and HCRW [10], the UK

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Standards for Public Involvement [16], and the Consensus Statement on Public Involvement & Engagement with Data-Intensive Health Research [15]. (These are summarised in Appendix 1.)

Principle 1
SAIL has a duty to work with the public and, consequently, has a strategic commitment to Public Involvement & Engagement
Commitment at the highest level is essential to ensure that Public Involvement & Engagement is properly resourced and respected as an integral part of the work of SAIL.

Principle 2
SAIL is committed to excellence in active and meaningful Public Involvement & Engagement
Public Involvement & Engagement activities must be of a high standard, they must involve an active, two-way process of dialogue and they must be meaningful to the audience.

Principle 3
SAIL respects heterogeneity and provides members of the public with a range of inclusive opportunities to engage and be involved
Public Involvement & Engagement activities must not be limited to particular sectors of society or cultural groups, and they should include opportunities to influence the development of our work and data-intensive research studies.

Principle 4
SAIL is committed to transparency, clarity of purpose and fostering respectful relationships in Public Involvement & Engagement activities
In working with the public, it is essential to provide clear, comprehensive, understandable information that enables people to contribute their views and properly engage in dialogue.

Principle 5
SAIL recognises and values the contribution of our staff for their Public Involvement & Engagement activities
In recognising that Public Involvement & Engagement activities take time, it is important that staff are supported and that their efforts are duly acknowledged by management.

Principle 6
SAIL assesses, reports and acts on the impact of involving and engaging the public
SAIL is committed to taking on board the views of the public in the development of our work and encourages researchers to do the same for their data-intensive studies.

Policy for Public Involvement & Engagement in the SAIL Databank

Based on the principles set out above, our overarching mission statement for Public Involvement & Engagement in the SAIL Databank is as follows:

> Mission statement
> At SAIL, we believe that we have a responsibility to work with the public in ways that promote inclusivity, that are proportionate and sustainable, and that demonstrate respect and

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trustworthiness. By enabling the voices of the public to be heard and included, we believe that our work is enriched.

Policy statements

Our policy statements are based are built around and underpinned by the set of principles set out above.

1) SAIL has a strategic commitment to Public Involvement & Engagement
   a) We embed Public Involvement & Engagement at all levels of our work and include members of the public in strategic planning.
   b) We have positioned strong leadership to champion Public Involvement & Engagement, and we foster a culture of Public Involvement & Engagement amongst our staff.
   c) We invest in dedicated posts to work on Public Involvement & Engagement activities and support all staff members to work with the public on relevant areas of their work.

2) SAIL is committed to excellence in active and meaningful Public Involvement & Engagement
   a) We endeavour to understand Public Involvement & Engagement, as appropriate to context, which is shared and used consistently across the organisation.
   b) We promote high standards by providing advice and guidance information to staff on good practice in Public Involvement & Engagement.
   c) We provide access to specialist training on Public Involvement & Engagement for staff and members of the general public.

3) SAIL respects heterogeneity and provides members of the public with inclusive opportunities to engage and be involved
   a) We aim to include members of the public at all levels of our work, including strategic direction and specific data-intensive research studies.
   b) We seek to be inclusive of all ages, ethnic groups, cultures, socioeconomic levels, lifestyles and other definable interests in our Public Involvement & Engagement activities.
   c) We recognise that there are limits to people's interest and seek to encourage, but not to coerce, inclusion.

4) SAIL is committed to transparency, clarity of purpose and fostering respectful relationships in Public Involvement & Engagement activities
   a) We aim to converse with the public in a clear way and to be transparent about our activities and the use of data in research studies.
   b) We recognise the importance of clarity of purpose in Public Involvement & Engagement activities to promote mutual understanding and so that suitable, realistic expectations can be set.
   c) We engender respectful, non-hierarchical relationships in our Public Involvement & Engagement activities.

5) SAIL recognises and values the contribution of our staff for their Public Involvement & Engagement activities

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a) We encourage managers to include scope for Public Involvement & Engagement, as appropriate, in workload planning and in induction for new staff.

b) We promote the benefits of Public Involvement & Engagement to all staff at all stages of their careers.

c) We communicate and celebrate our staff successes in Public Involvement & Engagement, and through this we encourage others to work with the public.

6) SAIL assesses, reports on and acts on the impact of involving and engaging the public

a) We promote Public Involvement & Engagement activities that are designed to produce impact in order to value the input of all who contribute.

b) We assess the impact of our activities and make modifications for improvement to maximise impact.

c) We are accountable for our decisions and ensure the outcomes of activities are duly taken into account and acted upon.

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Appendix 1. Summary of principles for Public Involvement & Engagement

The UKRI Concordat for Engaging the Public with Research is a set of principles drawn up by the funders of research in the UK [9]:

1) UK research organisations have a strategic commitment to public engagement
2) Researchers are recognised and valued for their involvement with public engagement activities
3) Researchers are enabled to participate in public engagement activities through appropriate training, support and opportunities
4) The signatories and supporters of this Concordat will undertake regular reviews of their and the wider research sector's progress in fostering public engagement across the UK

Health and Care Research Wales sets out the following ambition and aims [10]:

Ambition

A key priority in the Health and Care Research Wales Strategic Plan is the need to facilitate and enable wider public involvement, engagement and participation in health and social care research.

We aim to:

- develop a greater public awareness and understanding of research and its benefits;
- create an environment where the public feel empowered and enabled to become involved with or take part in research;
- ensure members of the public in Wales have opportunities to engage with, be actively involved in, and take part in research;
- establish Wales as a centre of excellence for active and meaningful public involvement and engagement in research.

The UK Standards for Public Involvement were drawn up by a partnership including representatives from the Chief Scientist Office (Scotland), Health and Care Research Wales, the Public Health Agency (Northern Ireland) and the National Institute for Health and Research (England) [16]:

1) Inclusive opportunities: Offer public involvement opportunities that are accessible and that reach people and groups according to research needs
2) Working together: Work together in a way that values all contributions, and that builds and sustains mutually respectful and productive relationships
3) Support & learning: Offer and promote support and learning opportunities that build confidence and skills for public involvement in research
4) Communications: Use plain language for well-timed and relevant communications, as part of involvement plans and activities
5) Impact: Seek improvement by identifying and sharing the difference that public involvement makes to research
6) Governance: Involve the public in research management, regulation, leadership and decision making

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The Consensus Statement on Public Involvement and Engagement with Data-Intensive Health Research was created by an international group of data-intensive researchers and Public Involvement & Engagement specialists [15]:

PI&E relating to data-intensive health research should:

1) Have institutional buy-in
2) Have clarity of purpose
3) Be transparent
4) Involve two-way communication
5) Be inclusive and accessible to broad publics
6) Be ongoing
7) Be designed to produce impact

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