



# SAIL User Forum

20th July 2023



# SAIL User Forum - Jul 2023

## 1. Welcome to SAIL user forum

Confluence page for all SAIL User Forum details:

<https://docs.hiru.swan.ac.uk/display/SUF>

## Some general house keeping points:



SAIL User forum's will not be recorded.



All slides will be shared after the forum via confluence.



Q&A is welcome via the chat or at designated points over video/audio.



Please mute microphones when not asking questions or presenting.

# SAIL User Forum - Jul 2023

## 1. Welcome to SAIL user forum

### SAIL user forums.. What to expect moving forward...



Forum frequency & timings – bi-monthly and on maintenance windows.



Forum chairs – Ashley Akbari & Chris Orton.



Forum structure & content – standing agenda, input from the community.



Forum contact – questions/suggestions [sailbusinessadmin@chi.swan.ac.uk](mailto:sailbusinessadmin@chi.swan.ac.uk)

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## 2. Talks

### **Mental Health Research**

Two talks (20 mins each):

#### **Talk 1: Data to Policy**

*Professor Ann John (Swansea University).*

#### **Talk 2: Children and Young People's mental health and well-being programme**

*Dr Annette Evans, Principal Statistician (Research and Evaluation Division Public Health Wales).*



# SAIL User Forum - Jul 2023

## 3. Data Acquisition and Governance

Cynthia Mcnerney

- Updates on new data sources / planned acquisition.



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## 3. Data Acquisition and Governance

### New Data Sources



A selection of the newly acquired anonymised data sources in the SAIL Databank include:

- ❖ Data First – Family Courts Dataset\*
- ❖ School Health Research Network (SHRN) – Student Health and Wellbeing Survey (2017, 2019 and 2021)\*
  
- ❖ Data First – Magistrate Courts Dataset\*\*
- ❖ Data First – Crown Courts Dataset\*\*
- ❖ Data First – Prisoner Custodial Journey Dataset\*\*
- ❖ Data First – Probation Dataset\*\*
- ❖ ONS - Census 2021 Data for England and Wales \*\*

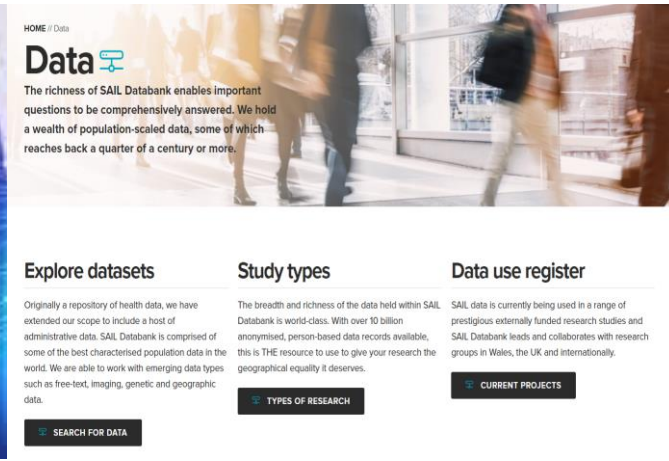
\* Available now

\*\* Available soon

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## 3. Data Acquisition and Governance

### Future Data Acquisitions

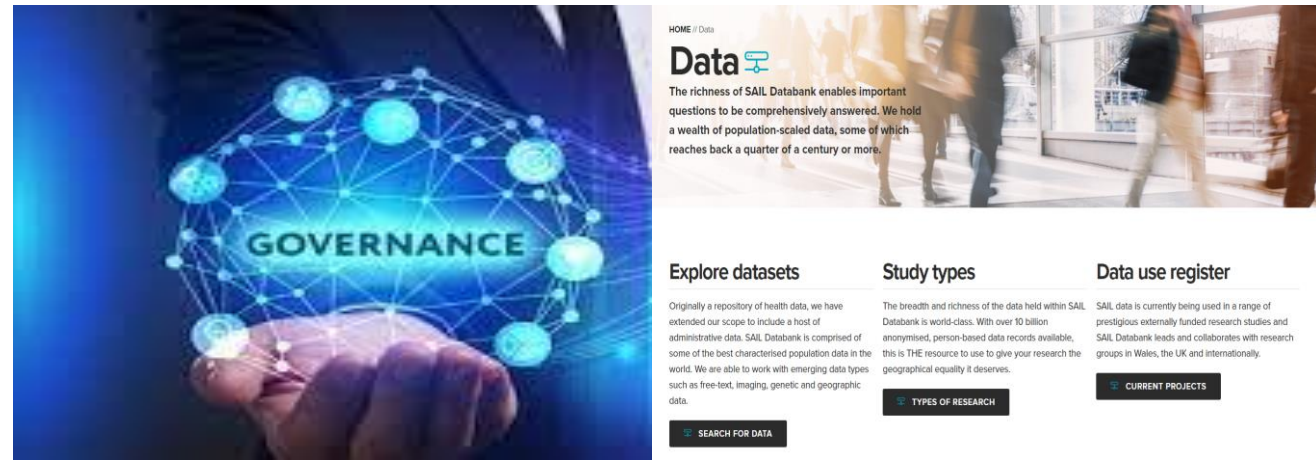


Some of the acquisitions currently being worked on include:

- ❖ ONS Annual Population Survey
- ❖ ONS COVID Infection Survey
- ❖ ONS Interdepartmental Business Register (IDBR) Data
- ❖ Data First – Civil Courts Dataset
- ❖ Universities and College Admissions Service (UCAS) data

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## 3. Data Acquisition and Governance



Information on existing SAIL data sources is available on:

<https://saildatabank.com/data/>

SAIL are continually working on refreshes/updates to our core data sources.

## Contact the Team

For any enquiries regarding new data acquisitions please email

Cynthia McNerney, Head of Data Acquisition and Provisioning

[c.l.mcnerney@swansea.ac.uk](mailto:c.l.mcnerney@swansea.ac.uk)



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## 4. Patient and Public Involvement and Engagement (PPIE)

Claire Newman

- Public engagement overview, and the SAIL Consumer Panel.





# SAIL DATABANK

Consumer  
Panel

Using Public data for public good

# Public insight



All users of SAIL Databank will have access to present their research ideas to our Consumer Panel made up of members of the public.



When assessing research proposals, Research Ethics Committees (REC) look favourably upon proposals which incorporate good quality public involvement at an early stage. This is evidence and reassurance to REC that the research being undertaken is ethically sound and in the public interest.



There can often be costs associated with assembling or sourcing a public panel to scrutinise research.



Access to our Consumer Panel is free of charge as a SAIL Databank user.

# The Panel's role includes;

- Acting as advisors on issues in research
- Advising on how best to engage with the public
- Offering guidance on how to recruit people to study steering groups
  - Providing views on data protection issues
  - Discussing proposals for research topics
- Examine whether the 'right' research questions are being asked
  - Reviewing information designed for a lay audience
  - Acting as advocates for data linkage research



## *Consumer Panel*

- Currently 16 members
- 62 % females
- Age range between 20-75
- Diverse backgrounds and knowledge
- Majority located in Wales, rural and urban

Researchers  
who involve  
members of the  
public run better  
studies because:

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they are more relevant to participants

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they are designed in a way which  
is acceptable to participants

---

they have participant information which  
is understandable to participants

---

they provide a better experience of research

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they deliver better communication of results  
to participants at the end of the study.

# Meetings

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4 –5 times a year, January, April, June, September, optional November

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Slots up to an hour, usually consists of presenting, discussion, asking the Panel questions and gaining feedback.

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Can attend at the beginning of research idea, interim results and on completion to communicate and disseminate findings.

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Panel can be used in a variety of ways, meetings, surveys, information sheets, patient facing document etc.....

# Researcher Feedback

- 'That was a really great discussion – thank you to you and the Panel for some excellent points!'
- We received invaluable feedback which will support our SAIL application and we were able to discuss and mitigate any concerns on using patient data for our research outcomes.”
- Meeting with the Panel is always valuable
- It helped the design of the research from the outset and made it more focused and meaningful.



# Research project examples

- **Better Outcome through Linked Data- Substance Misuse Pilot** presented to the Panel in April 2022.- <https://www.gov.uk/government/publications/ministry-of-justice-better-outcomes-through-linked-data-bold/ministry-of-justice-better-outcomes-through-linked-data-bold>
- **NDL Wales** continue to use the Panel to present their research - [New study examines differences in mental health hospital attendances for children & young people in Wales - SAIL Databank](#)
- **Dr Emily Lowthian** visited the Panel in January 2022 - <https://saildatabank.com/educational-pathways-for-looked-after-children/>
- **The Consumer Panel** has recently been mentioned in a recent report from the **ONS** - [https://osr.statisticsauthority.gov.uk/wp-content/uploads/2023/07/202307\\_office\\_statistics\\_regulation\\_data\\_sharing\\_linkage\\_report.pdf](https://osr.statisticsauthority.gov.uk/wp-content/uploads/2023/07/202307_office_statistics_regulation_data_sharing_linkage_report.pdf)

For further information on PPIE, the Consumer Panel, or to book a presentation slot, please email me at [claire.newman@swansea.ac.uk](mailto:claire.newman@swansea.ac.uk).

Any Questions?

# SAIL User Forum - Jul 2023

## 5. Analytical services



Sarah Rees and Dan Thayer

- Dataset and linkage updates (new WLGP cleaned view).
- ALF-2.
- Meta-data and documentation update.
- SAIL good practice (file out requests / well-behaved SQL).

# Analytical Services Update



Daniel Thayer

Senior Data Scientist – Team Lead, SAIL Analytical Services

# Output Reviews – Thanks for your Patience

- Steps being taken
  - Adding team capacity
  - Will be reviewing policy/process
- How you can help us
  - Request out minimum necessary
  - Review intermediate results inside gateway
  - Please fully document requests
- SAIL Output User Guide on SAIL Gateway Wiki

# Cleaned GP Dataset

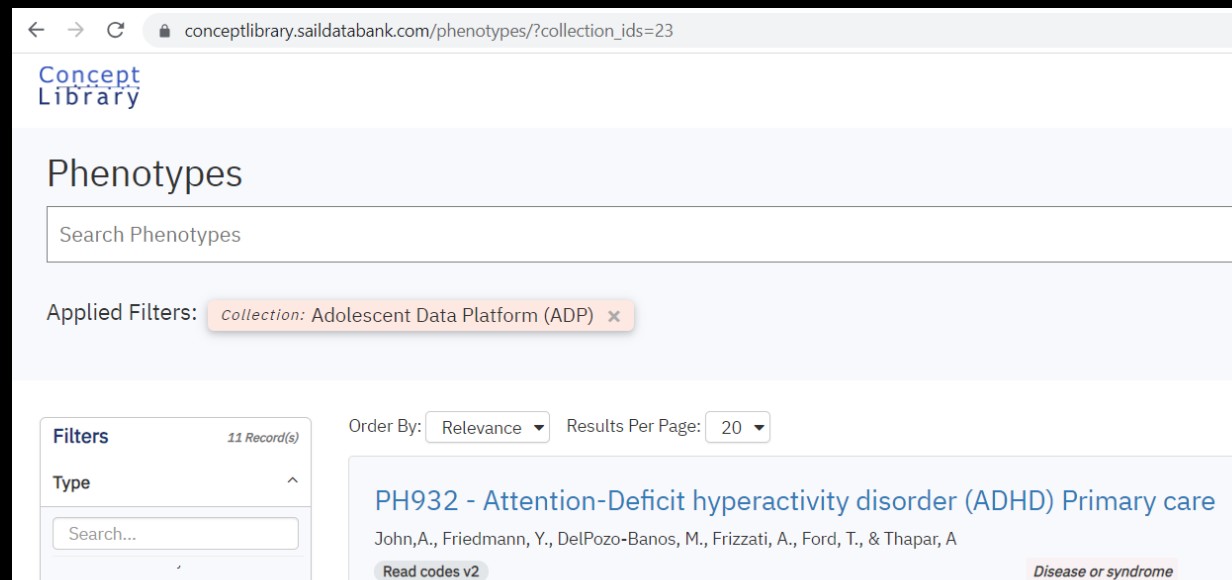
- event\_cd replaced with a numeric ID that links to a code table.
- Advantages:
  - Storage space/performance (20 character field replaced with integer field for 3 billion rows).
  - Metadata about Read codes integrated in table.
    - Description
    - Whether Read v2, v3
    - Read code categorization (medication, diagnosis, ...)
    - More to be added in future.
- Provisioned to new projects by default
- Available to existing projects on request (no refresh charge)

# ALF2 Is Here

- Probabilistic linkage of datasets beyond Wales using new algorithm (Linxmart).
- Rather than linking to one gold standard (WDS), links everything to everything.
- Updates to data may change existing linkages, ALF2 may change with updates.
- Currently linked:
  - Family Court
  - Cafcass
- No immediate impact on standard SAIL projects (Wales data only).

# Resources available

- Wiki page for writing efficient, well-behaved SQL queries.
- SAILDBUtils R package for working with the database.
  - Python version under development.
- Concept Library: create, use, and share code lists and other definitions ([conceptlibrary.saildatabank.com](http://conceptlibrary.saildatabank.com))



The screenshot shows the Concept Library website interface. The browser address bar displays `conceptlibrary.saildatabank.com/phenotypes/?collection_ids=23`. The page title is "Phenotypes" and includes a search bar labeled "Search Phenotypes". Below the search bar, an "Applied Filters" section shows "Collection: Adolescent Data Platform (ADP)" with a close button. On the left, a "Filters" sidebar indicates "11 Record(s)" and has a "Type" dropdown menu with a search input. The main content area shows "Order By: Relevance" and "Results Per Page: 20". A search result is displayed for "PH932 - Attention-Deficit hyperactivity disorder (ADHD) Primary care" by John, A., Friedmann, Y., DelPozo-Banos, M., Frizzati, A., Ford, T., & Thapar, A. The result includes a "Read codes v2" button and a "Disease or syndrome" label.



# Other updates

- Team annual report released.
- Any questions?

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## 6. Technical services



Richard Hier

- Updates on technical services and developments.

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## 7. Marketing & Comms



Chris Roberts

- Updates from SAIL marketing and communications



# SAIL Databank Impact & Communications

**Chris Roberts**

Senior Impact & Engagement Officer



# SAIL Survey

# Thank You!



## The SAIL Databank Annual User Survey

We'd like to hear about your experience of using SAIL Databank to improve our systems, services and support for your research.

This survey contains up to 30 questions taking 5-10 minutes to complete.

What type of organisation do you work for? for e.g. University, NHS, Government etc.

Is your research related to COVID-19?

- Yes
- No

Have you undertaken previous research using SAIL Databank to that of your current/most recent project?

# Survey results

Were you satisfied with the format, structure and quality of your data and metadata?

66 out of 69 answered



Were you satisfied with any guidance or instructions you received once your data was ready for use?

68 out of 69 answered



## The SAIL Databank User Newsletter

April 2023 (Spring)



### SAIL Databank User Annual Survey 2022/23.



This is your chance to tell us about your experiences using SAIL Databank. We greatly value your feedback, good or bad, so please tell us what you think. The user survey is a very important tool for us to improve our services and systems which enables us to enhance support for your research.

> [Click here to access the SAIL Databank user survey](#) <

# SAIL's Newsroom (website)

HOME // Newsroom

## SAIL Databank Newsroom

All Blog Events Impact News



IMPACT

### Wales Covid-19 Evidence Centre Review 2021-2023

JULY 10, 2023

The Wales COVID-19 Evidence Centre (WCEC), funded by Welsh Government through Health and Care Research Wales, has published its final "legacy" report showcasing two years ...



NEWS

### Groundbreaking research examines how the sequence of disease acquisition affects life expectancy

JUNE 30, 2023

New research, led by Population Data Science at Swansea University Medical School, published in The Lancet Public Health, examines how co-existing diseases develop over time ...



EVENTS

### Swansea University 3rd year students receive SAIL Databank public & patient involvement group insight

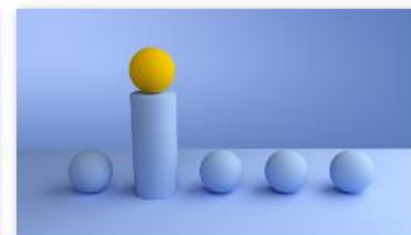
JUNE 12, 2023

In April of this year, SAIL Databank showcased this year's cohort of Swansea University Medical School students who will be using SAIL Databank as part ...



BLOG

### Blog: Long-term effectiveness of



IMPACT

### The value of SAIL Databank for clinical



IMPACT

### Impact of National Core Studies

# SAIL's socials



Home



Explore



Notifications



Messages



Lists



Bookmarks



Communities



Verified



Profile

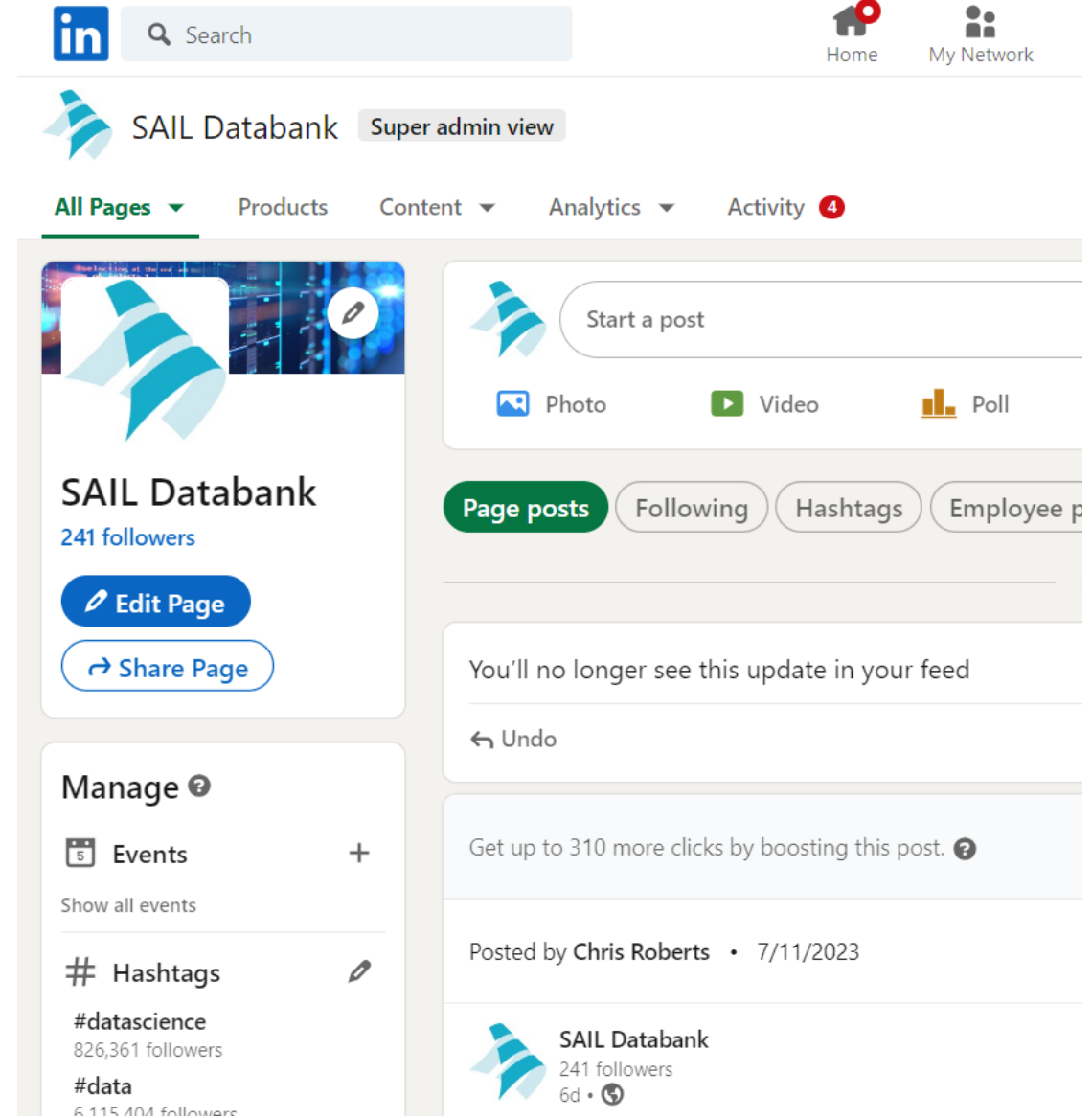
← **SAILDatabank**  
163 Tweets



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@SAILDatabank

SAIL Databank is a rich and trust  
For technical support please con  
[@SAILDatabank\\_Cy](#)

Swansea University [saild](#)



in Search Home My Network

SAIL Databank Super admin view

All Pages Products Content Analytics Activity 4

Start a post

Photo Video Poll

Page posts Following Hashtags Employee p

You'll no longer see this update in your feed

Undo

Get up to 310 more clicks by boosting this post.

Posted by Chris Roberts • 7/11/2023

SAIL Databank  
241 followers  
6d •

Manage

Events +

Show all events

Hashtags

#datascience  
826,361 followers

#data  
6,115,404 followers



# SAIL's Annual Reports

## Study into link between mental health and substance abuse issues on young people's mortality.

New research which has been published online in the journal, *Clinical Epidemiology*, has revealed that young people with a history of mental health and drug issues are more likely to die than those with a mental illness or who use substances alone. The study found that more than 70 per cent of young people with substance use mentioned in their health data also had a record relating to mental illness.

The study also found that males and those from the most deprived areas are at greatest risk of death. Researchers also found that while incidence of young people with both mental illness and substance use in their hospital admissions data remained stable, in GP practice records it decreased in the most deprived part of Wales and increased in the least deprived areas. This may be because the number of young people with these conditions in those deprived areas is reducing; alternatively, it may be because fewer young people in these areas are accessing services or are having this information recorded in their patient history. The full paper can be found here: [https://www.dovepress.com/articles.php?article\\_id=72260](https://www.dovepress.com/articles.php?article_id=72260)

**"The work of ADR Wales and SAIL Databank on ADR UK themes such as housing and communities, children and young people, health and well-being and particularly Covid-19 have constructively informed policy decisions and improved the lives of many people in Wales."**

-Dr Emma Gordon,  
ADR UK Director

## £17m funding for ADR Wales' collaborative data research in Wales.

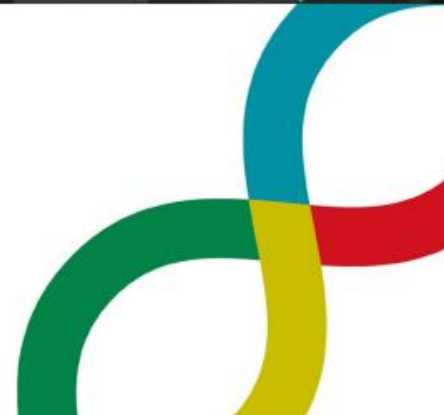
Administrative Data Research Wales (ADR Wales) has been awarded £16,985,944 refunding until 2026 as part of the £90 million UK wide Administrative Data Research UK (ADR UK) investment by the Economic and Social Research Council (ESRC), part of UKRI.

ADR Wales is a well-established programme which aligns its work with the key areas identified in the Welsh Government's Programme for Government 2021-2026 such as education, mental health and housing. It utilises the academic independence and expertise of a team of specialist researchers, analysts, and data scientists, working in partnership with SAIL Databank and played a pivotal role in informing understanding and subsequent decision making at policy level during the pandemic in both Wales and across the UK.

Dr Emma Gordon, ADR UK Director said: "We are delighted to award ADR Wales funding to continue their important administrative data research and data linkage programmes. The work of ADR Wales and SAIL Databank on ADR UK themes such as housing and communities, children and young people, health and well-being and particularly Covid-19 have constructively informed policy decisions and improved the lives of many people in Wales. This funding extension is testament to the fantastic impact that ADR Wales and SAIL Databank have delivered so far".  
Read more about this at: <https://popdatasci.swan.ac.uk/17m-funding-for-collaborative-data-research-in-wales/>



## 2021 - 2022 Annual report



## University helping to improve medicine safety in early motherhood.

Researchers from Swansea University and SAIL Databank have teamed up with colleagues from across Europe to produce their first publication as part of the IMI ConcePTION project.

This £28 million Europe-wide project is funded by the Innovative Medicines Initiative (IMI); a joint undertaking, which receives support from the European Union's Horizon 2020 research and innovation programme and the European Federation of Pharmaceutical Industries and Associations (EFPIA).

IMI seeks to bridge the knowledge and data gap in the safety of medicines prescribed during pregnancy and breastfeeding. It aims to do this by creating a trusted information ecosystem using anonymised data from multi-national data sources.

Congenital Anomaly Register and Information Service (CARIS) Manager David Tucker said: "This has been an exciting project. It uses the routine data collected by CARIS to its full potential. This research is answering long-asked questions about children's survival, quality of life and educational achievements. These are questions which every parent asks and now we are beginning to provide some answers."

Further details can be found at: <https://popdatasci.swan.ac.uk/university-helping-to-improve-medicine-safety-in-early-motherhood/>



**"This research is answering long-asked questions about children's survival, quality of life and educational achievements. These are questions which every parent asks and now we are beginning to provide some answers."**

- David Tucker,  
Public Health Wales



# SAIL's wider impact

## SAIL DATABANK - POPULATION DATA SCIENCE



IMPACT

### Wales Covid-19 Evidence Centre Review 2021-2023

The Wales COVID-19 Evidence Centre (WCEC), funded by Welsh Government through Health and Care Research Wales, has published its final "legacy" report showcasing two years ...



IMPACT

### Impact of National Core Studies Immunity Programme

Led by Health Data Research UK (HDR UK), in partnership with the Office for National Statistics, The National Core Studies programme was established in Summer ...



IMPACT

### Developing learning health systems in the UK: Priorities for action

This report, by the Health Foundation and Health Data Research UK is the final output of the Better Care Catalyst programme's policy and insights workstream, ...



IMPACT

### Better, Broader, Safer: Using Health Data for Research and Analysis

'...the excellent work at SAIL/SERP, and very substantial delivery outside of health data research in adjacent communities such as genomics and physics, where open collaborative ...

# SAIL in the press



March 13, 2023

## Study reveals Impact of pandemic on incidence of long-term conditions in Wales

A population data linkage study using anonymised primary and secondary care health records in Swansea University's **SAIL Databank** has revealed that in 2020 and 2021, fewer people in Wales were being diagnosed with long-term conditions than expected.



June 30, 2023

## Groundbreaking research examines how the sequence of disease acquisition affects life expectancy

New research, led by Population Data Science at Swansea University Medical School, published in *The Lancet Public Health*, examines how co-existing diseases develop over time and how they impact patient outcomes and healthcare resources.

# SAIL at events

MEDIWALES  
**connects**  
NHS COLLABORATION CONFERENCE



Contact us if interested in taking part in a blog, news stories or other dissemination around your new funding / work / outputs.

[Christopher.Roberts@Swansea.ac.uk](mailto:Christopher.Roberts@Swansea.ac.uk)

## SAIL User Forum - Jul 2023

8. Time for questions and discussion from the SAIL community



Anyone at the meeting today – any questions?



# SAIL User Forum - Jul 2023

## 9. Feedback



We will request feedback after each forum, we are keen to hear how we can improve the forums moving forward and tailor them to be more impactful & useful to the SAIL community.

Please contact the SAIL email with any feedback or requests for changes please.

# SAIL User Forum - Jul 2023

## 9. Feedback



Are you interested in presenting at a future SAIL user forum?

Do you have any requests for areas of research / developments you would like to hear about at the next forum or in the future?

Please contact SAIL by **Wed 9<sup>th</sup> Aug** [sailbusinessadmin@chi.swan.ac.uk](mailto:sailbusinessadmin@chi.swan.ac.uk)



# SAIL User Forum - Jul 2023

## 9. Feedback

Confluence page for all SAIL User Forum details: <https://docs.hiru.swan.ac.uk/display/SUF>

SAIL User Forums for 2023 will be on *(other SAIL/SeRP maintenance window dates on the website):*

Thursdays (10:00 - 12:00)

- Thu 21<sup>st</sup> September 2023

All the dates are available on Confluence.

*The eventbrite link will be shared in August.*



Any further questions...

Thank you for coming



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