

Unlocking the power of the **patient voice** with AI



White Swan



White Swan is a Registered Charity (1176486)

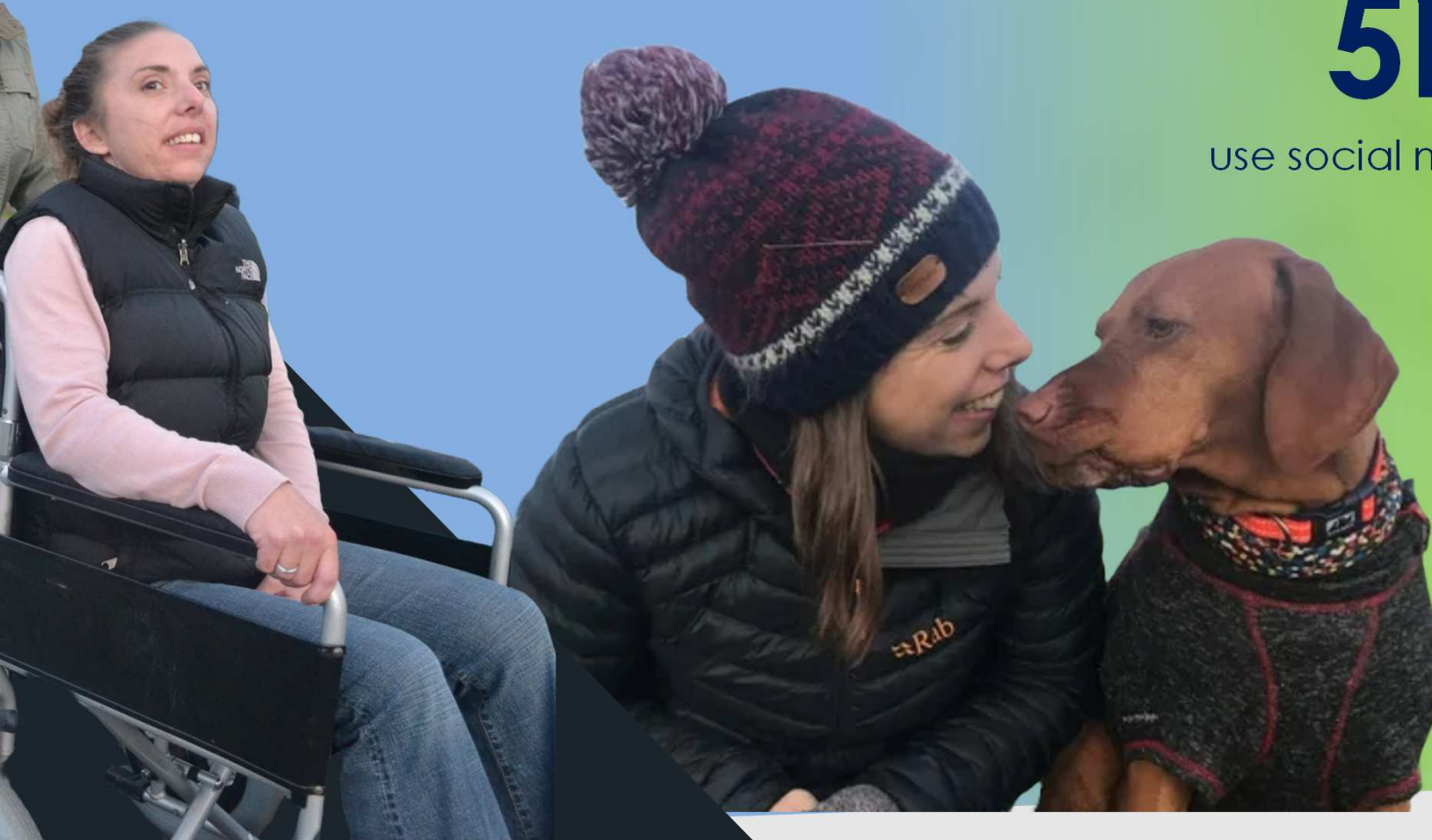
Social Media Data has the power
to **save and improve** lives.

5bn

use social media globally

80%

use to benefit health



A background image of a globe showing the Americas, overlaid with a network of grey dots and lines representing global connectivity. The top left corner has a blue gradient, and the top right has a green gradient.

The Opportunity:

Harness the power of the patient's voice by leveraging millions of social conversations online using AI to improve health outcomes

Introducing White Swan

- ✓ **Registered charity** with a mission to **improve the health of society**
- ✓ **Proprietary tools and AI**
- ✓ **Published methodology**
- ✓ **Dedicated team of experts**
- ✓ **Providing pioneering insights for our partners**



The ROYAL MARSDEN
NHS Foundation Trust



UNIVERSITY OF
BIRMINGHAM



THE KINETIX GROUP
Powered by Petauri™



Patient-centric data-driven insight across the journey



Horizon scanning
& identifying
unmet needs



Accelerate
diagnosis



Clinical trial design
& development



Increase treatment
adoption &
adherence



Improve patient
engagement &
comms



Inform policy and
improve care

Diagnosis

Treatment

Living with Condition

Healthcare Orgs

Researchers

Clinicians & Patients

Leveraging our Million Minds Insights Platform



Global Reach Accesses an unlimited anonymised dataset, segmented by language, country



Accesses hard-to-reach groups
Such as rare disease patients, at scale



Increased depth & unbiased design
Patients share much more anonymously, are listened to vs asked



Multiple Segmentations Such as condition, co-morbidities, symptoms, treatments, lifestyle and risk factors, outcomes



Agile and Fast
Ability to deep dive into key areas and flex questions/focus.



Integrated clinically validated datasets (Human Phenotype Ontology, Disease Ontology, International classification of diseases, ORPHA.NET)



Proprietary tools and taxonomy Built on White Swan knowledge graph IP, leverages Black Swan algorithms & tech



We access >565k data sources

Patient's Lived Experience



Reddit

430M+ active monthly users



Boards

500K+ other online forums



HealthUnlocked



Reviews

200+ sites



Walgreens



(hospital reviews)



Image-led Social

Billions monthly active users*



Advocacy, News, & Education



Micro-blogging

600M+ monthly active users*



Blogs

20M+ articles

PHYSICIAN'S WEEKLY

GreenMedinfo[®]
The Science of Natural Healing

PubMed



News

45K+ sites

nature

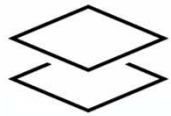
BioSpace[®]

PHARMIWEB.COM
Global Pharma News & Resources

Pillars of Million Minds

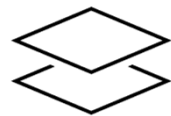
Clinical Specialism Datasets

Curated, Cleansed, De-Duped



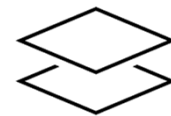
Entire Clinical Specialisms

Ontology, Cardiology,
Rheumatology & Muscular
Skeletall, Dermatology....



Specific Clinical Areas

Dementia, Menopause,
Parkinson's, Mental Health

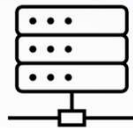


In Development

Gastroenterology,
Immunology, Haematology....

Data Models / NLP

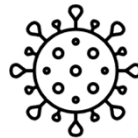
Enriching, Clustering



Taxonomies
Topic Clustering



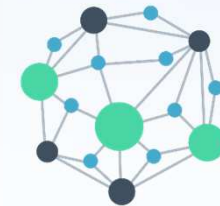
Named entity recognition
Entity Linking
Relationship extraction



Context Relevance
Author Authenticity

Knowledge Graph

Connecting, Querying



Nodes: entities of interest
E.g. Symptom, Condition, Side Effect....

Properties: Each node has its own set
of properties. E.g Label (such as shortness
of breath, cross ref's (e.g. SNOWMED code)

Relationships (between nodes): E.g. "Risk
factor for", "Side effect of", "Mentioned
with"....

Case Studies

Health Care



Accelerating Diagnosis in Cardiology



University Hospitals
Birmingham
NHS Foundation Trust



Objective

Understand key features of Hypertrophic Cardiomyopathy to accelerate diagnosis and improve effectiveness of disease management



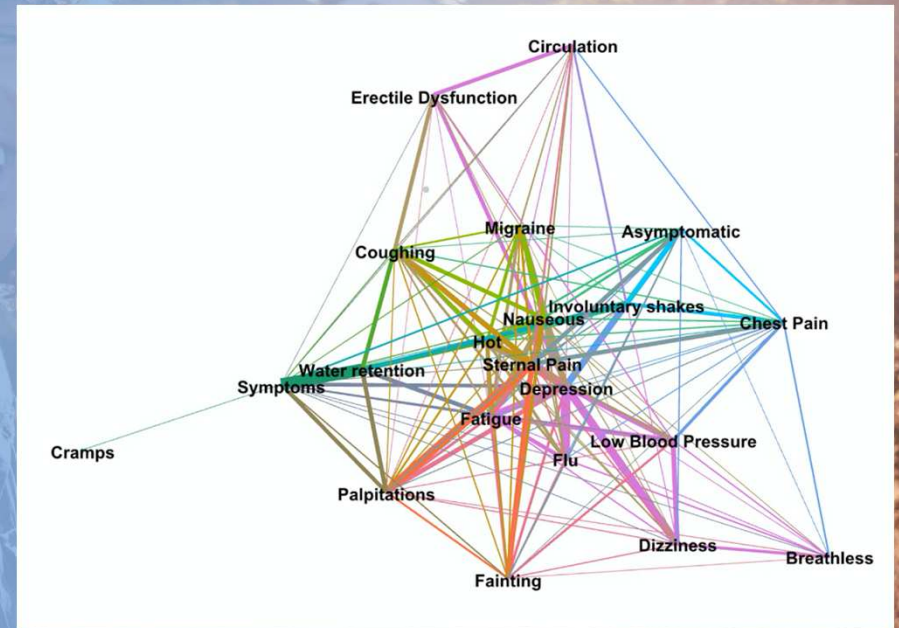
Data Analysis

>18k conversations



Outcome

An innovative quantitative symptom map to support clinical diagnosis. Identified new target group uniquely placed to spot early symptoms to education to accelerate diagnosis.



Case
Study

Improving Cancer Care

The ROYAL MARSDEN
NHS Foundation Trust



Objective

Understand opportunities to improve patient experience in Royal Marsden Hospital



Data Analysis

>26k conversations (short and long form)



Outcome

Clear findings and recommendations to inform the Royal Marsden patient care strategy presented, including areas not previously identified through traditional patient surveys.

“We want to be at the forefront of patient care, so I was genuinely excited when I read the report – this has the potential to have a significant positive impact on patient experience at the Royal Marsden”

Chief Nurse, Royal Marsden

**Case
Study**

Improving Clinical Trial Design



Objective

Understand and gain actionable insights from patients on their experience with the condition from diagnosis to enhance clinical trial design.



Data Analysis

>50k datapoints from 50m global documents



Outcome

Robust and actionable insights getting to the 'why' behind barriers to current adherence and adoption, to support NICE approval of new treatment innovation.

*We were delighted with the work that White Swan delivered, which helped us gain a **greater understanding of the patient's needs and inform our clinical trial design.** The insights were robust and actionable and at every stage the team were incredibly responsive, professional and enjoyable to work with.*

*Kerry Kriel,
Early Asset Strategist*

**Case
Study**

Informing Strategic Priorities



Objective

Understand patient and carer experiences from diagnosis to end of life care to identify their greatest needs to inform and shape development of future charitable services



Data Analysis

>3 million conversations over 3 months



Outcome

Key unmet patient and carer needs identified, including tipping points for support

3

Aggressive and violent behavior is a key concern. While deterioration and loss of cognitive function are expected outcomes, aggression can be an unwelcome surprise, as well as being dangerous for both families and sufferers. Appropriate specialist care is essential to suit patient needs.

4

There is a genuine fear and mistrust of care homes both for families and sufferers. Fears exist around poor quality of care and excessive costs. Family members feel guilt and under pressure to do more to provide the best care possible for their loved one, sometimes at a cost to their own health and wellbeing.

5

Exercise & Music are the top preventative lifestyle steps talked about online. While the majority of online discussion focusses on symptoms, carers and support, conversation around prevention frequently references research claiming that regular exercise of body and mind helps prevent and alleviate symptoms of Dementia.

Case Study

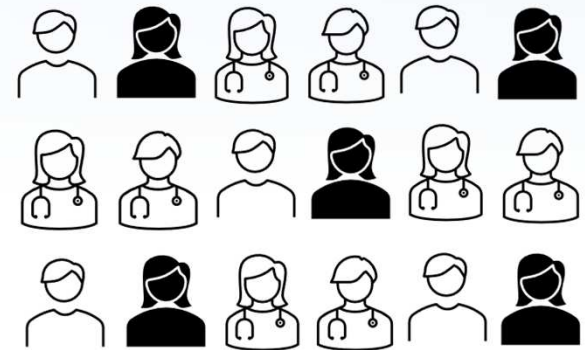
Researchers

Creating a Bespoke
Interface to Million Minds
(in development)



Unlocking Insight into Real-Life Patient Experiences for Researchers

- **Data democratisation.** Enables access social data a fraction of the cost and time of ingesting, processing, storing and cleaning the data themselves.
- **Discover deep 'whys' behind behaviours** – compliments the 'what' data sources to discover unmet needs, patient priorities, barriers and opportunities.
- **Validated methodology.** We set standards on how to curate and cleanse social data, supported by published papers, to ensure that our novel approach is validated
- **Pre-Proposal Validation & Hypothesis Testing:** Understand data availability and opportunities for analysis
- **Gap analysis:** Understand gaps in existing academic research and how this maps against patient priorities



Future Innovation

Supporting Clinicians
and Patients to
Accelerate Diagnosis



The Problem / Opportunity

Millions of people are living undiagnosed, not knowing what is wrong with them or what to do about it.



500
million people

living undiagnosed globally

1 in 17

have a rare disease
at some point in their lives

£3.6bn NHS cost

in GP appointments alone for

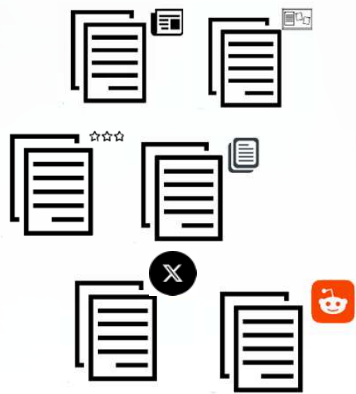
Long delay
to diagnosis

5.6 years

+ 8 clinicians

+ 3 misdiagnosis

Supporting Accelerated Diagnosis



Online social data

- NLP/Models
- named entity recognition
 - entity linking
 - entity relationship extraction

“social” entities and relationships

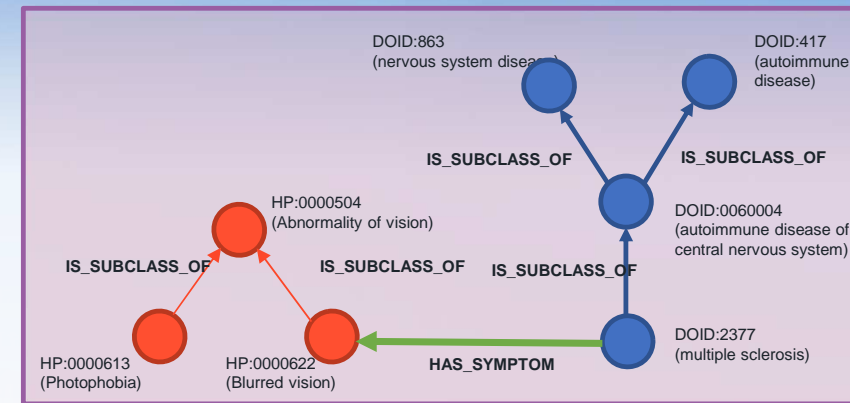
- Comorbidities
- Lifestyle factors
- Treatment side-effects
- ...

Expert knowledge

“Symptom” entities based on Human Phenotype Ontology (HPO)

“Condition” entities based on Disease Ontology (DO)

With cross-refs to other ontologies e.g. MeSH, ICD, SNOMED etc



Combines collective patient experience to help patients with their clinicians get to a diagnosis faster.

In Summary

- ✓ Social data offers huge potential to improve health outcomes
- ✓ There is powerful insight accessible across the patient journey to accelerate diagnosis, improve treatment and care
- ✓ LLMs are accelerating our ability to cleanse and analyse
- ✓ Opening-up access to researchers could transform patient-centric advances
- ✓ Future innovation has the potential to support clinicians and patients to accelerate diagnosis



White Swan

Thank you

For more information visit

www.whiteswan.org.uk

Or contact me

miranda@whiteswan.org.uk