From clinic to cohort: The VOICE vitiligo registry & bio-resource as a blueprint for high-fidelity specialist registries

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Andrew Wildman[1], Charlotte L. R. Curtis[1], Megan King[1], John Ferguson[2]

[1]Momentum Data Ltd, Pendragon House, 65 London Road, St Albans, UK
[2]St John's Institute of Dermatology, Guy's and St Thomas' NHS Foundation Trust, London, UK

Context

Vitiligo is a chronic skin depigmentation condition.
It is often highly visual and can cause considerable psychological distress.

Rationale & Objectives

Existing routine data lack detailed information. We created a **high-fidelity registry, integrating multiple data-sources, in an NHS specialist care setting.**

Methods

The Vitiligo Registry and Bio-resource (VOICE) integrates **five years** of data collected from consented children and adults attending the UK's only specialist vitiligo service.

Data collected

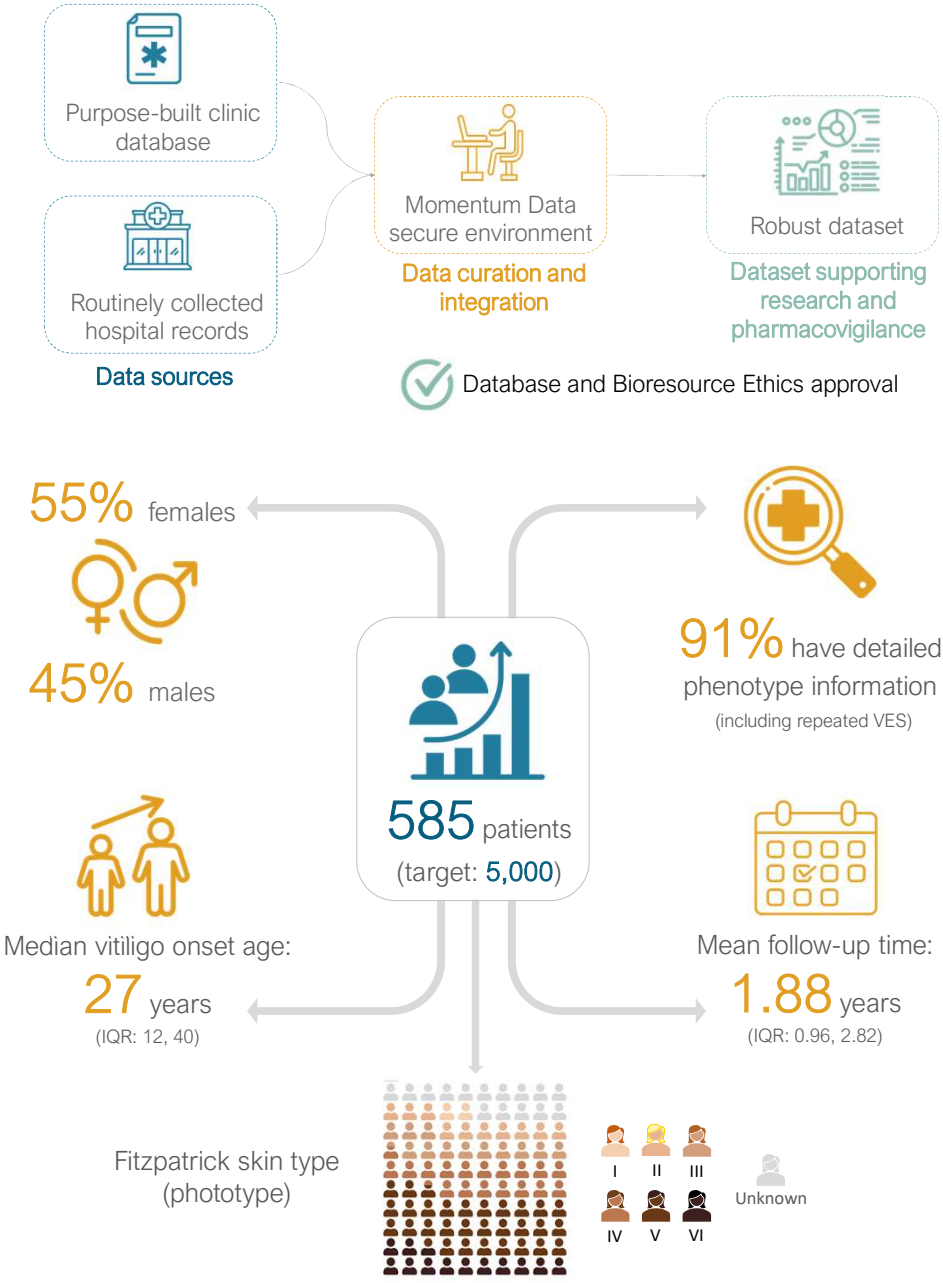
NHS Specialist Care
- Complete capture of all care
- Full blood analysis
- Topical and systemic treatments

Demographic & Vitiligo Data
- Age, sex, ethnicity, skin type
- Vitiligo onset and progression
- Vitiligo Extent Score (VES)
- Lesion features
- Autoimmune family history

Patient Reported Outcomes
- Validated quality-of-life and psychological measures (BIPQ, DLQI, VIPS, SSCI-8)

Potential Future Data Integration
- Genetic information
- Linkage to primary care (permissions already in place)

Results



BIPQ, Brief Illness Perception Questionnaire; DLQI, Dermatology Life Quality Index; IQR, interquartile range; SSCI, Stigma Scale for Chronic Illnesses; VES, Vitiligo Extension Score; VIPS, Vitiligo Impact Patient Scale.

Conclusions

The VOICE is the **largest high-fidelity vitiligo registry created to date**, which can **facilitate world-leading clinical and health economics vitiligo research**. It also provides a **blueprint for developing similar high-fidelity specialist registries** for other conditions.

MOMENTUM
Real World Evidence

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