The prevalence of hidradenitis suppurativa is shown by the Secure Anonymised Information Linkage (SAIL) Databank to be one per cent of the population of Wales

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Dear Editor, Hidradenitis suppurativa (HS) is a chronic inflammatory skin disease with multiple inflammatory skin lesions (‘boils’) in flexural locations.1 Prevalence of HS remains controversial2,3 and the study aim was to search the Secure Anonymised Information Linkage (SAIL) Databank to identify diagnosed and undiagnosed HS cases in Wales, UK.

The SAIL Databank provides access to routinely collected primary care data, linked to Patient Episode Database for Wales (PEDW) data, covering 2-5 million individuals within the Welsh population of just over 3 million people.4 The prevalence of diagnosed cases of HS was determined using Read Codes M25y1 and M25y111. Undiagnosed ‘proxy’ cases were identified using the skin boil algorithms developed and validated for the UK Clinical Practice Research Datalink (CPRD).3 The algorithms require a record of at least five skin boils, on separate occasions within the primary care databank. Validation in CPRD makes use of General Practitioner (GP) questionnaires, which are limited by GPs having several thousand patients under their care, and so GPs themselves are often reliant on the electronic record. While SAIL does not have access to GP validation, it is linked to HealthWise Wales (HWW), a register of people willing to take part in research and return health questionnaires.5

An online questionnaire was sent to HWW participants to identify outbreaks of skin ‘boils’ during the previous 6 months in flexural locations and a minimum of two boils. The questionnaire has a published specificity of 97% and a sensitivity of 90% in identifying people with HS.6 Of the 1481 SAIL participants who answered the questionnaire, 86 (5.8%) gave responses consistent with HS. Five of these individuals had a HS Read Code in SAIL and 14 were identified by the CPRD algorithms. Manually checking a representative sample of the other 67 positive respondents, there were no relevant consultations, such as for skin boils or pilonidal sinus, recorded in SAIL. Due to a lack of data, validation of CPRD algorithms was possible for subalgorithm 2(b) only, for which eight HWW respondents gave positive responses and 31 were negative for HS (21% positive rate).

From the SAIL population of 2 531 943 individuals, 11 397 had an HS diagnosis in SAIL up to 30 June 2017. A further 1585 SAIL patients were treated for HS in secondary care as identified by PEDW data. Hence, the point prevalence of diagnosed HS in the Welsh population was 5.1 per 1000, or 0.51%. Application of the CPRD hierarchical subalgorithms identified 74 594 additional proxy cases, reduced to 14 435 criteria-diagnosed cases after validation, using the conversion factors developed in the CPRD study3 and the HWW-validated conversion factor for subalgorithm 2(b). Overall HS prevalence is therefore 10.8 per 1000, or 1.08% (Figure 1).

Of the 100 HS patients attending a specialist secondary care HS clinic in Wales, 85 of the cohort were present in SAIL, 72 as diagnosed cases and a further nine within the subalgorithms, with four cases not captured. This confirms relatively high capture of secondary care HS cases by SAIL, with 85% correctly transcribed into the primary care record and only 5% missed by either the diagnostic code or a subalgorithm.

During the period from 2000 to 2016, the number of newly diagnosed HS cases per year increased nearly fourfold, from 200 to 765, likely owing to increasing recognition of HS. The female-to-male ratio of newly diagnosed cases was 3 : 1 and peak age of diagnosis was in the third decade of life.

Limitations of the study include a relatively short time frame for HWW data collection, which was only able to validate subalgorithm 2(b) in this cohort. However, CPRD covers Wales, as well as the English population, and so validation data for CPRD will also be valid for the Welsh population. The 5.8% rate of positive returns from the HWW questionnaire is high and indicates a degree of case ascertainment bias. Lack of relevant SAIL consultations in most of this group suggests that either the individuals had mild disease or they chose not to see their GP, or both. Our prevalence figure may be an underestimate because HWW data were used only as a validation tool for SAIL data.

Comparing the SAIL results with prevalence figures from CPRD, there is quite close agreement. Prevalence of diagnosed cases in CPRD was 5.4 per 1000 (0.54%).7 Prevalence of HS in CPRD rose to 0.77% when validated proxy cases were included, and 1.19% when probable cases with a history of 1–4 flexural skin boils on separate occasions were included.8 The SAIL prevalence of 1.08% adds further weight to the evidence that HS is a relatively common condition in the UK.
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Conflicts of interest: J.R.I. is Editor-in-Chief of the BJD. He is a consultant for UCB Pharma, Novartis, Viela Bio and Kymera Therapeutics; he received travel expenses and a speaker’s honorarium from UCB Pharma. The remaining authors declare they have no conflicts of interest.

Figure 1 Data sources and their contributions to the overall hidradenitis suppurativa (HS) prevalence figure and validation process. SAIL, Secure Anonymised Information Linkage Databank; CPRD, Clinical Practice Research Datalink; HWW, HealthWise Wales.

SAIL population = 2 531 943
HS diagnostic Read Codes = 11 397 individuals
Proxy cases from application of CPRD subalgorithms = 74 594
Additional individuals receiving HS treatment in hospital = 1585
Conversion factors applied from CPRD study and HWW responses = 14 435 validated cases
Total cases = 27 417
Prevalence = 27 417/2 531 943 = 1.08%