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FEASIBILITY OF A NOVEL DISEASE PROGRESS REPORTING SYSTEM TO FACILITATE SHARED DECISION MAKING BETWEEN PHYSICIANS AND PATIENTS IN SLE

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Background The Australian Lupus Registry and Biobank (ALRB) is a longitudinal database of clinical information on SLE patients, with data imported from different sources. The current reporting system does not offer an integrated module that allows visualisation of patients clinical, laboratory and treatment changes. This presents an opportunity for developing a new interactive interface, where physicians and patients can view the historical data to facilitate better informed treatment decisions.

Methods A survey of clinicians who are familiar with the Australian Lupus Registry is done to ascertain required visual elements, forming the user requirement document that captures the clinicians requirements and specifications. The system was developed in JavaScript programming language, utilising the D3.js, CanvasJS, and jquery libraries. The system was implemented using the evolutionary prototyping approach.

Results Our developed interactive web application allowed clinicians to customise the viewing of relevant data for a particular patient, by combining the display of changes in laboratory results and medications in a time-dependent graph. We employed the multiple-axis line graph data visualisation technique, with dynamic axis scaling during zooming in, that allows users to view multiple selected parameters with varying units of measurement. A control panel allows for filtering results to show up to four plots at one time in a single graph, so that relationship between these variables can be viewed in a time-dependent manner. The timeline can be displayed using zooming and panning techniques, while hovering on a point on the graph shows a tooltip of the exact numerical values of a measurement for that timeframe.

Conclusions An interface that can promote physician-patient shared decision-making practice has been developed and proven to be feasible. The integration of a disease progress reporting system into a platform that is used primarily for clinical research can encourage users to have added value when longitudinal data is collected for primary research purpose. The utility of this reporting system will need to be further evaluated in a large-scale study.

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EPIDEMIOLOGY OF JUVENILE SYSTEMIC LUPUS ERYTHEMATOSUS IN 2016–2017: INCIDENCE, PREVALENCE AND AGE OF ONSET

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Background The epidemiology of juvenile systemic lupus erythematosus (jSLE) varies among ethnic groups and countries and up-to-dated results on Asian population are not recently reported. The purpose of the present study was to investigate the prevalence and incidence of jSLE in Korea.

Methods Data were collected from the exclusive national health claims database of Korea, which is covering more than 95% of the patient population. JSLE was identified using the diagnostic code M32 from the Korean Standard Classification of Diseases. Patients under 18years-old, who had at least one claim for jSLE between January 2016 to December 2017 as a primary or secondary final diagnosis were included in the study. Data encompass both outpatient and hospitalization records. SAS 9.4 and R package was used in data extraction and cleaning.

Results We estimated sex- and age-specific prevalence and incidence of jSLE during the period. The prevalence of jSLE (95% CI) decreased from 5.85 (5.845.87) per 1 00 000 persons in 2016 to 5.35 (5.345.37) per 1 00 000 persons in 2017. The incidence of jSLE (95% CI) was 2.20 (2.192.21) per 1 00 000 persons in 2017. The prevalence and incidence of jSLE were higher in women than in men (4.87 per 1 00 000 in men vs.42.32 per 1 00 000 in female in prevalence of 2016, 2.74/100,000 in men vs. 10.00/100,000 in women in incidence of 2017). By change point analysis, female age of 13 in incidence and 15 in prevalence was detected as a uprising age.

Conclusions The prevalence of jSLE in Korea was lower than Hawaiian natives and comparable with Canadian, Taiwanese and Japanese. Female with post-pubertal age was detected as a population of increasing change point.

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Abstract 224 Figure 1 The number of prevalent patients of juvenile systemic lupus erythematosus by sex