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A tool to assist rheumatologists to engage their lupus patients: the Purple Butterfly

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Abstract

Objective: Translating the highly technical medical jargon of SLE into understandable concepts for patients, their families and individuals without expertise in SLE is a serious challenge. To facilitate communication and enable self-management in SLE, we aimed to create an innovative visual tool, the Purple Butterfly.

Methods: We selected clinically representative criteria for SLE and transposed them as graphical features in an attractive and meaningful visual. We developed a script in R programming language that automatically transposes clinical data into this visualization. We asked SLE patients from a local cohort about the relevance, usefulness and acceptability of this visual tool in an online pilot survey.

Results: The innovative Purple Butterfly features 11 key clinical criteria: age; sex; organ damage; disease activity; comorbidities; use of antimalarials, prednisone, immunosuppressants and biologics; and patient-reported physical and mental health–related quality of life. Each Purple Butterfly provides the health portrait of one SLE patient at one medical visit, and the automatic compilation of the butterflies can illustrate a patient's clinical journey over time. All survey participants agreed that they would like to use the Purple Butterfly to visualize the course of their SLE over time, and 9 of 10 agreed it should be used during their medical consultations.

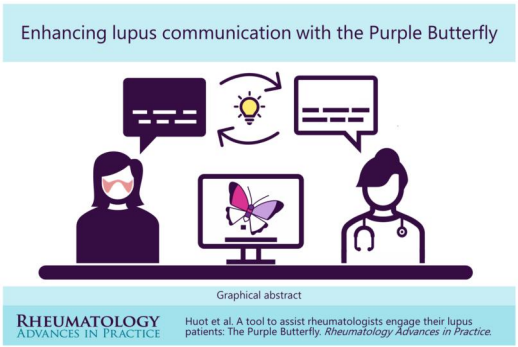
Conclusion: The Purple Butterfly nurtures effective doctor–patient communication by providing concise visual summaries of lupus patients' health conditions. We believe the Purple Butterfly has the potential to empower patients to take charge of their condition, enhance healthcare coordination and raise awareness about SLE.

Lay Summary

What does this mean for patients?

We created the Purple Butterfly, a visual tool specifically developed for people with lupus that promotes self-management. Lupus is a complex arthritic disease with unpredictable symptoms manifesting across the body. Each person's experience with lupus is unique, and collaboration between patients and their healthcare professionals is fundamental for efficient management. The Purple Butterfly improves doctor–patient communication by presenting concise summaries of one's health in an easy-to-understand yet clinically rigorous visual format. Like an interpreter between patients and healthcare providers, this innovative tool can foster knowledge sharing, clarify goal setting for individualized care and enhance the overall quality of care around lupus.

Graphical Abstract



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Keywords: systemic lupus erythematosus, health status, patient participation, self-management, human, data visualization.

Key messages

- We implemented the Purple Butterfly, the first visual tool designed specifically for SLE that provides global and immediate insight into the patients' lupus-relevant health status.
- We transposed raw clinical data into engaging yet rigorous images that will facilitate patient–physician communication and prompt ownership, engagement and empowerment in SLE patients.
- The Purple Butterfly allows visualization of the intricate and diverse journeys of SLE patients over time in an appealing yet clinically convenient medium.

Introduction

SLE is a chronic, inflammatory autoimmune disease that predominantly affects women [1–3]. With a poorly understood underlying cause, SLE manifests in various ways [4] and exhibits substantial heterogeneity [5, 6].

Efficient management of SLE requires sustained and coordinated interactions among patients, physicians and multiple medical specialists and healthcare professionals. Due to its wide range of visible and invisible symptoms, unpredictable trajectories and flares, SLE is particularly hard on patients' physical, psychological and social well-being [7–9]. Recognizing the complexity of this disease calls for a more comprehensive and holistic approach [10] that actively involves patients and empowers them toward self-care [11].

Patients who demonstrate high activation, i.e. who have the ability and willingness to take responsibility for their health and healthcare, often experience improved health-related outcomes across a broad spectrum [12]. This patient activation is influenced by various factors, including effective doctor–patient communication [13]. In the case of chronic multi-organ illnesses like SLE, gathering a thorough medical history, conducting comprehensive physical examinations and performing a battery of laboratory tests [14] yields a complex set of clinical data that expands and reshapes over each follow-up visit. Translating the highly technical medical jargon of lupus into concepts that patients, their families and individuals without expertise in SLE can understand is a serious challenge.

Data visualization converts raw and complex data into visual representations [15]. By transforming a cognitively taxing process into a perceptual one, data visualization offers a valuable solution to support the health management of individuals with various chronic conditions [16]. In our pursuit to increase communication, engagement, ownership and empowerment in the context of SLE, we developed a user-friendly and visually appealing tool called the 'Purple Butterfly'. This tool consolidates relevant SLE features into a convivial visual that instantly informs about the clinical course of a patient. By utilizing the Purple Butterfly, patients can take greater ownership of their journey, enabling them to ask more pertinent questions, make informed decisions and actively participate in their own care.

Materials and methods

Ethics

Ethical approval was granted by the CHU de Québec-Université Laval Ethics Committee and patients provided informed consent to participate in the survey (2023-6446).

Tool conceptualization

This task entailed selecting representative, meaningful and revealing clinical criteria that could adequately describe an SLE patient's overall health portrait. The selection was based on a senior rheumatologist's expertise, know-how and needs. The selected clinical criteria were then elaborated as the Purple Butterfly's graphical features. These include age; sex; organ damage; disease activity; comorbidity; treatment with antimalarials, corticosteroids, immune-suppressing drugs and biologic agents; and patient reports on their physical and mental health.

Automation

Using the R programming language (R Foundation for Statistical Computing, Vienna, Austria), we defined the butterfly's shapes, colours, fills and line types. Functions were implemented to automatically generate butterfly images from each patient's clinical data and consolidate all Purple Butterfly images from each patient's clinical visits into a single file.

Patient survey

To evaluate how the Purple Butterfly would be received by persons living with SLE, we recruited participants to complete a survey. Individuals were part of a local cohort dedicated to systemic autoimmune rheumatic diseases; these patients presented a medically confirmed diagnosis of SLE. The questionnaire was developed by the authors and reviewed by a patient partner before online distribution.

The survey (Supplementary Table S1, available at *Rheumatology Advances in Practice* online) consisted of 26 questions divided into two sets. A 3-min explanatory video of the Purple Butterfly tool was presented between the two sets of questions. In the first set, 3 questions collected demographic data and 12 questions collected information about context, such as disease duration, collaboration between the different health professionals, the social and familial network of the participant and the impact of lupus on their lives. In the second set, five questions were related to the composition of the Purple Butterfly tool itself, two were about its potential role/utility and four were about its use. The questions were answered using levels of agreement. If the participants expressed a disagreement about the Purple Butterfly's composition, they had an opportunity for free-text statements. At the conclusion of the survey, participants were invited to submit additional comments and suggestions.

Survey data were collected and managed using the REDCap electronic data capture tool hosted at the Centre de

recherche du CHU de Québec-Université Laval [17, 18]. Descriptive statistics were generated for all items. To simplify the interpretation and analysis of the level of agreement questions, the answers 'totally agree' and 'rather agree' were combined, as were the answers 'totally disagree' and 'rather disagree'. Association tests (chi-squared test) or logistic regressions could not be performed, as in several cases, only one modality was observed for one variable. Therefore, only descriptive statistics are reported.

Results

The Purple Butterfly graphically transposes 11 key clinical criteria

To shift the focus from data to people and make the invisible visible, we devised a visual representation depicting the patient's lupus health condition. As a framework, we selected the butterfly as universally associated with lupus because of its depiction of the most visible and characteristic sign of lupus, the butterfly-shaped facial rash (Fig. 1). Morphing of the Purple Butterfly from a concept to a tool was achieved by programming a script that automatically transposes patients' clinical data into graphical features.

Figs 2 and 3 summarize all the Purple Butterfly's features and explain how to read it. The age of the patient is indicated by the number between the lower wings (Fig. 2A), and the butterfly's tilt refers to the sex of the patient (Fig. 2B). A rightward tilt represents a woman, a leftward tilt represents a man and an upright butterfly represents individuals who self-identify as other. Dots on the antennae show the extent of organ damage (Fig. 2C). Every point of damage holds prognostic significance and is thus represented accordingly, with each dot on the antennae corresponding to one point on the SLICC Damage Index. Because it is cumulative and irreversible, damage is depicted in a discrete manner in the Purple Butterfly.

The butterfly's lower wings indicate the patient-reported quality of life, in terms of physical health [Physical Component Summary (PCS) score] on the left and mental health [Mental Component Summary (MCS) score] on the right (Fig. 2D). For those two summary scores of the 36-Item Short Form Health Survey (SF-36), 50 represents the average quality of life of the general population. Thus scores are displayed relative to that average, with a complete wing accommodating 50 white lines. The more lines a wing has, the higher the score and the better the quality of life. Five-line intervals are darker for easier reading. When PCS or MCS scores exceed 50, a flounce is added to the corresponding wing, indicating an above-average patient-reported quality of life.

The disease activity is portrayed in the upper left wing, using the SLEDAI 2000 (SLEDAI-2K); the upper right wing indicates the comorbidities, using the Charlson Comorbidity Index (CCI) (Fig. 3A and B). Both the SLEDAI-2K and CCI are represented through a colour code that is sensitive to people with colour blindness. Each clinical endpoint has its own range of low, moderate and high values, but the colour scale remains consistent across the Purple Butterfly for ease of interpretation. The colour code gravitates around purple, the colour associated with SLE awareness, with a redder hue trending toward higher/worse clinical scores.

The Purple Butterfly's body, including the head, chest and mid- and lower-body parts, is dedicated to the main classes of treatment (Fig. 3C). The head depicts the use of antimalarials, the chest depicts prednisone or prednisone equivalent and the mid- and lower-body sections depict immunosuppressive drugs and biologics. The presence or absence of medication is indicated by a closed (dark purple) or open (white) body part, respectively. As high doses and prolonged use of prednisone can lead to organ damage, information regarding prednisone dose is conveyed through the colour code. Throughout the Purple Butterfly, white denotes a null value for a given criterion. Dotted outlines result from absent or missing data.

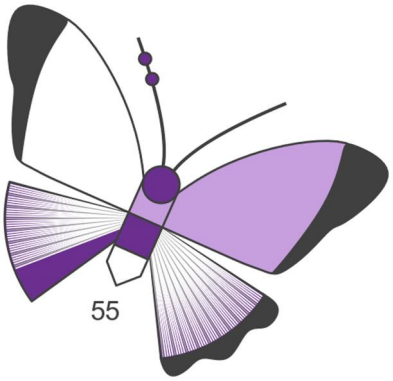


Figure 1. The Purple Butterfly tool. Each butterfly provides the health portrait of an SLE patient from one medical consultation

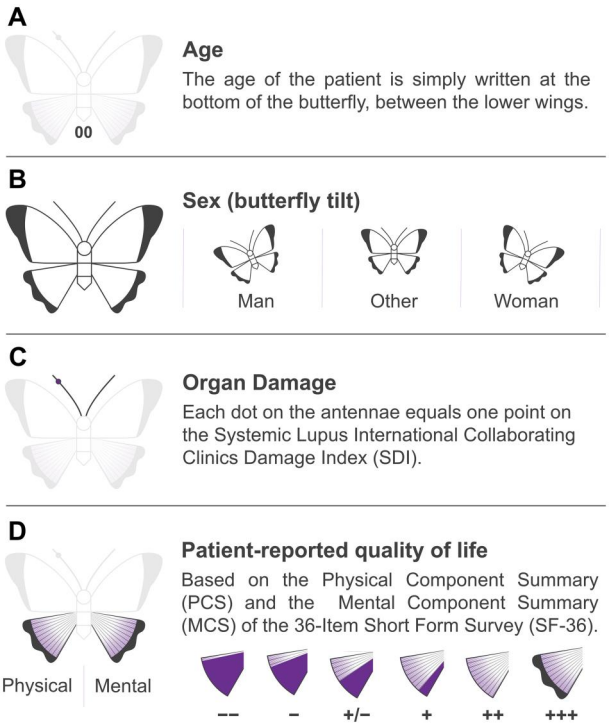


Figure 2. Description of the non-coloured features that shape the Purple Butterfly

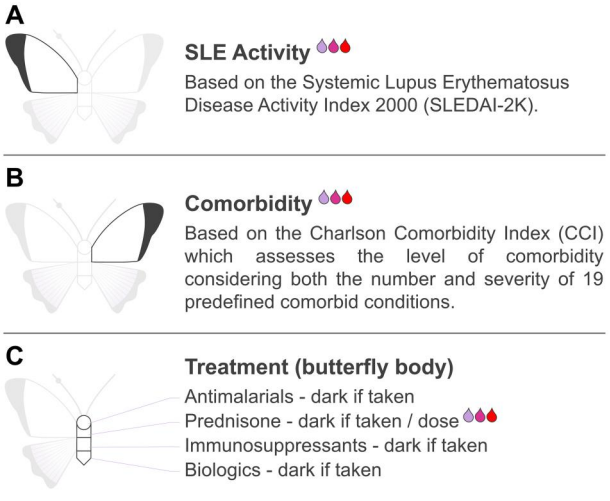
Purple Butterfly image suites efficiently summarize the complex and heterogeneous journey of SLE patients

We devised a script that streamlines the generation and compilation of the butterflies composing a patient's clinical journey. Figs 4–6 provide examples of clinical trajectories from distinct SLE patients over time.

Fig. 4 depicts the disease course of a 35-year-old woman whose prednisone doses and disease activity fluctuated widely over the years, as shown by the Purple Butterfly's chest and upper left wing, respectively. The butterfly's body also indicates ongoing use of antimalarial drugs (head) and intermittent use of immunosuppressive drugs (mid-part). The lower right wing indicates a significant improvement in the patient-reported mental quality of life at the age of 44.

For a 62-year-old woman (Fig. 5), the Purple Butterfly's body illustrates continuous use of antimalarial drugs (head), with a slow decrease in prednisone dose over time (chest) and the addition of immunosuppressive drugs from time to time (mid-part). The antennae reveal extensive damage accumulation in the span of barely a year, between 62 and 63 years of age. Disease activity remained absent for several months thereafter, as indicated by the upper left wing. The lower left wing reveals a decline in the patient-reported physical quality of life, especially between the ages of 63 and 64 years.

Finally, a 59-year-old male patient is represented in Fig. 6. His immunosuppressive drug was interrupted at age 60 (the butterfly's mid-body part), while other medications remained constant. The upper left wing indicates a reduction in disease activity, although the upper right one shows a significant increase in the comorbidity score. A worsening of the condition, illustrated by four additional points of damage on the antennae, can also be observed over time. Overall, the Purple Butterfly effectively summarizes the intricate and diverse journeys of patients with SLE in an easy-to-understand, yet rigorous, visual.



D	None	Low	Moderate	High
SLE Activity (SLEDAI-2K)	0	1 - 7	8 - 11	≥ 12
Comorbidity (CCI)	0	1 - 2	3 - 4	≥ 5
Prednisone dose (mg/day)	0	≤ 5	> 5 - 29	≥ 30

Figure 3. Description of the Purple Butterfly colour-coded elements. As non-available results are highly important to distinguish from a 'none criterion', the outline of the unavailable item is presented with a dashed line (- - - - -)

Patients are interested in using the Purple Butterfly—results from the survey

To test the validity and usefulness of the Purple Butterfly, we conducted an online pilot survey with SLE patients from a local cohort. Ten participants completed the questionnaire (demographics are described in Supplementary Table S2 and Supplementary Fig. S1, available at *Rheumatology Advances in Practice* online). Patient agreement levels were high regardless of age, education, duration of illness, current state of health, medical care, social and family network and lupus impacts. The statements with the highest level of agreement were on the colour code's applicability and ease of understanding, as well as willingness to use the Purple Butterfly to track the evolution of their lupus over time.

Theme 1: patient-optimised Purple Butterfly composition

Nine participants found the butterfly symbol to be appropriate for the tool (Q13) (Supplementary Fig. S1B, available at *Rheumatology Advances in Practice* online). All agreed that the colour code was adequate and easy to comprehend (Q14). Nine agreed with the method used to represent damage, while one disagreed, requiring additional details (Q15). Eight participants agreed that the method used to represent the quality of life suited them (Q16). Based on their feedback, we made an adjustment to the lower wings: as quality of life

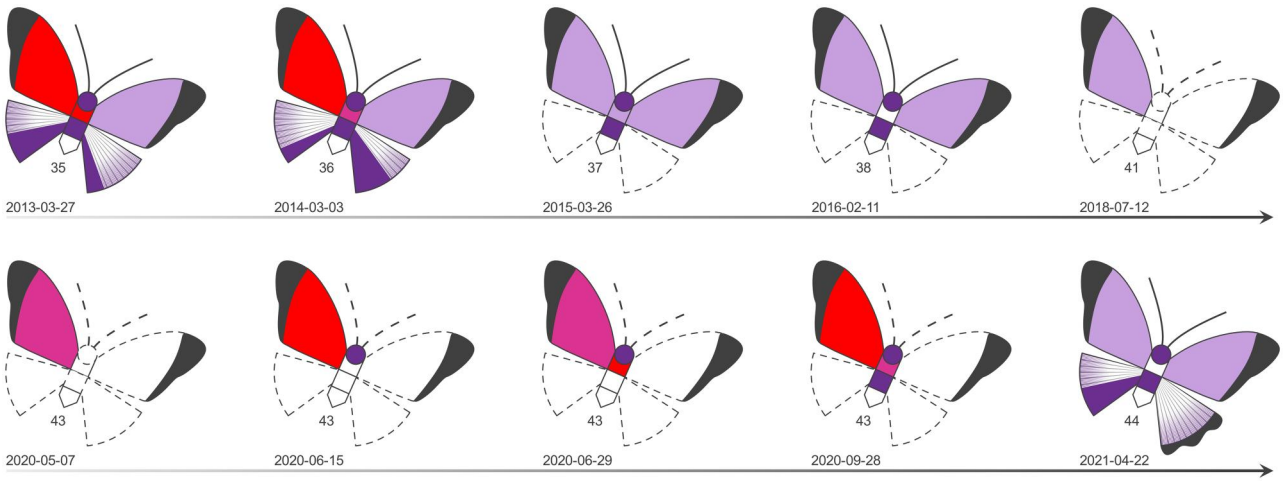


Figure 4. Series of Purple Butterflies summarizing the course of illness of one SLE patient over nearly 10 years. Complete visits are easily recognized from interim visits, as the latter display several shapes with a dashed outline, representing information not collected at the interim visits

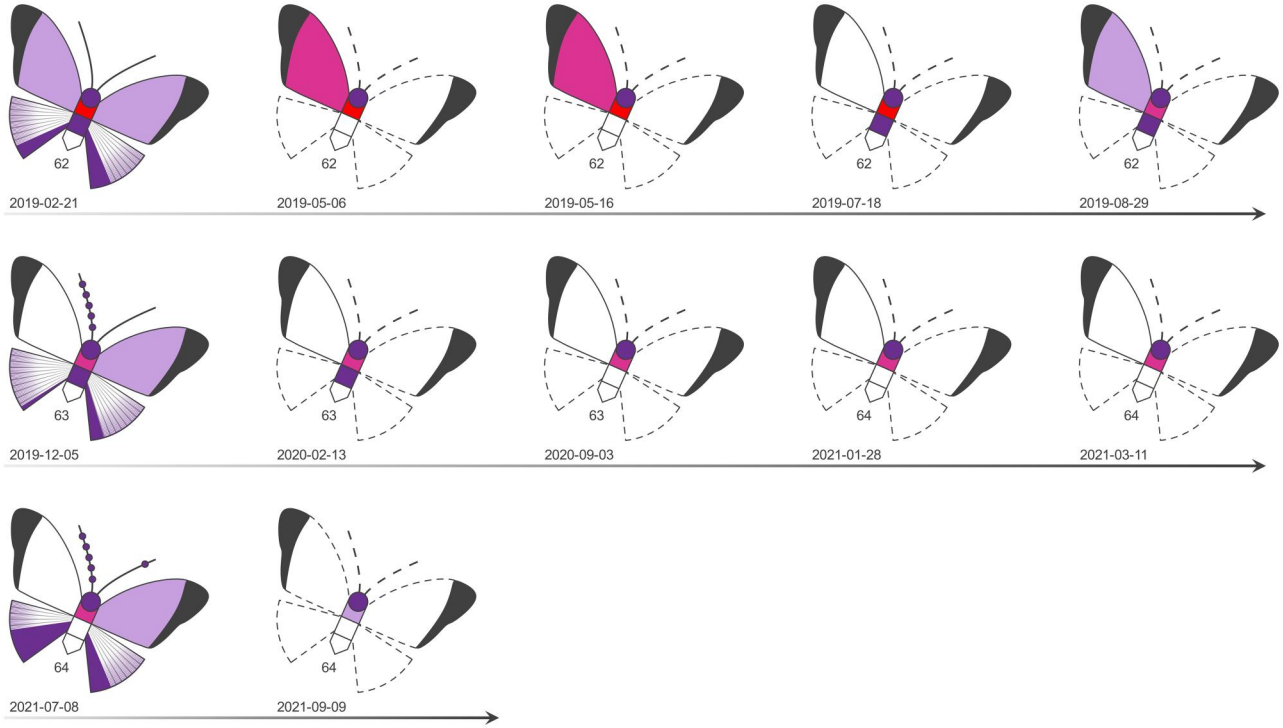


Figure 5. Purple Butterflies presenting the illness course of one SLE patient over a 2-year period. Complete visits are easily recognized from interim visits, as the latter display several shapes with a dashed outline, representing information not collected at the interim visits

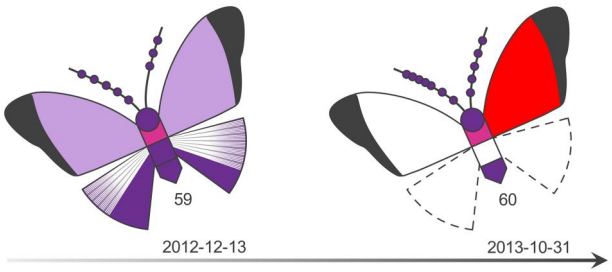


Figure 6. Duet of Purple Butterflies depicting the clinical evolution of a male patient with SLE

improves, the dark lower wings gradually lighten with the white line addition. This patient-optimized Purple Butterfly is the version presented herein. When participants were asked if they would like to add more criteria to the Purple Butterfly, 9 of 10 indicated no, but 1 suggested including a measure of daily pain experienced.

Theme 2: role/utility of the Purple Butterfly

Seven participants believed that the Purple Butterfly could help them better understand their disease (Q18), while nine believed it could improve communication with their healthcare team (Q19).

Theme 3: use of the Purple Butterfly

Nine participants agreed that they would like the Purple Butterfly to be used during their clinical follow-up visits (Q20), seven intended to use it to talk about lupus with family and friends (Q21) and seven believed that incorporating the Purple Butterfly in their lupus care and management could benefit them (Q22). Although no image depicting a patient's SLE progression was shown during the questionnaire's explanatory video, all participants agreed that they would like to use the Purple Butterfly to visualize the course of their lupus over time (Q23).

After completing the survey, some participants commented positively, stating that the Purple Butterfly was a good visual summary of the disease. One participant mentioned that the tool allowed for a more empathetic approach, while another highlighted the importance of doctor–patient communication and teaming up quickly to develop an appropriate treatment plan.

Discussion

In this work we developed the Purple Butterfly, a novel tool that utilizes data visualization to provide a multidimensional summary of SLE patients' health journeys. The Purple Butterfly transforms complex SLE-specific medical data into a reliable and user-friendly visual format, fostering communication between patients and healthcare providers. By establishing a visual connection between complex clinical data and patients' real-life journeys, the Purple Butterfly may help instil a sense of ownership, empowerment and capability in patients and provide the basis for sound treatment decisions.

Access to the Purple Butterfly tool should be immediately feasible for all patients recruited in SLE research cohorts, as these cohorts are likely to possess more comprehensive medical records and datasets. Ongoing efforts are focused on enabling the seamless utilization of the Purple Butterfly in the routine clinical care of local and national SLE cohorts. In this context, we are developing a subscription-model app, more specifically a software as a service (SaaS) app, for clinics treating patients with lupus. We also plan to include features enabling manual data entry for provider- and patient-reported outcomes, thus extending the Purple Butterfly's

applicability beyond research cohorts. To ensure the Purple Butterfly remains aligned with the dynamic field and clinical requirements of SLE (as indicated by LupusQoL [19], SLEQOL [20, 21]), as well as cater to the specific needs of diverse regions and cohorts, the indexes and criteria of the Purple Butterfly can be adjusted accordingly. The upper wings' dark sections can incorporate additional details pertaining to different SLE cohorts, thus maintaining clarity, rigour and consistency across eventual variations of the Purple Butterfly.

Healthcare data visualization [22–24] and graphical tools aiming to better equip physicians in their practice [25–28] have been developed in various ways. Diverging from existing approaches, the Purple Butterfly is specifically designed for SLE, is visually appealing yet clinically convenient and consolidates patient and physician perspectives, which makes it particularly suitable for lupus management. The Purple Butterfly also provides a distinctive resource for undergraduate medical education programs to address the acknowledged lack of medical training on SLE [29, 30]. Furthermore, the Purple Butterfly's ability to visually describe entire cohorts of SLE patients opens doors for interdisciplinary networks and collaborations, thereby enhancing the overall network of care.

Given SLE's invisible manifestations, patients often feel misunderstood by the public, their employers [8], their general practitioners and even by their loved ones [9], advocating a need for increased lupus awareness [9, 31]. The Purple Butterfly offers an attractive, yet rigorous and meaningful interface for this purpose, and aspires to make readers feel empathy toward the patients whose data are portrayed. This visualization concept, known as anthropographics [32, 33], may help patients feel more understood and supported.

The next phase of development includes evaluation of the Purple Butterfly in an actual care facility setting, thus verifying how well received the tool is by the users. The feedback from patients and healthcare teams will enable us to make enhancements that fit specific requirements, both for the Purple Butterfly and use of the SaaS app during consultations.

The underlying concept of the Purple Butterfly tool offers a broad scope of applications in the knowledge transfer context, notably as a catalyst for the development of novel visual tools and mnemonic models. By leveraging this innovative approach, new tools can be created to enhance understanding and communication for various conditions dealing with complex datasets.

In conclusion, we created an innovative tool that holds great promise for individuals with SLE and their healthcare teams. The Purple Butterfly not only provides a concise history of lupus patients' health status over time, but it also serves as a facilitator of effective patient–physician communication, empowering patients to take charge of their condition. Universal adoption of the Purple Butterfly has the potential to strengthen international collaborations, enhance SLE education, improve healthcare coordination and raise awareness about SLE globally. The Purple Butterfly represents a significant advancement in knowledge transfer methodologies, with far-reaching implications for patient care and interdisciplinary collaborations.

Study limitations

The Purple Butterfly's characteristics are largely based on the vast experience of a senior rheumatologist. As we deploy the Purple Butterfly to additional cohorts of patients, adjustments may become necessary. Also, perceptions regarding the Purple Butterfly will become more representative with increasing numbers of patients completing the survey. In particular, we aim at recruiting a sufficient number of men and people from different ethnicities so that population statistics can be applied.

Supplementary material

Supplementary material is available at *Rheumatology Advances in Practice* online.

Data availability

The data underlying this article are available in the article and in its online supplementary material.

Authors' contributions

S.H. designed the study, conceived the Purple Butterfly, produced the ethics, conducted the survey, analyzed the data, wrote most of the manuscript; P.R.F. designed parts of the study and survey, reviewed the manuscript; A.G. contributed to the ethics and parts of the survey; C.L. contributed to the ethics; M.P. contributed to the study design, analyzed the data, wrote the final version of the manuscript.

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Disclosure statement: P.R.F. participates on the lupus advisory boards of AstraZeneca, GSK and AbbVie. The remaining authors declare no conflicts of interest.

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