



Epicensus: The Drive to Elevating the Standard of Care for Patients with Psoriasis

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COMMENTARY

Since publication of our paper “Elevating the standard of care for patients with psoriasis: ‘Calls to Action’ from Epicensus, a multistakeholder

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pan-European initiative” [1], we, the Steering Committee, questioned what actions have been taken to address the care gaps that were identified? Here we update readers on activities we are aware of across Europe that have arisen from or that align with the Calls to Action (CTA) developed in respect to the Epicensus programme.

The Epicensus programme is a pan-European initiative that was designed to gain insight into the current standard of care (SoC), identify gaps and develop clear CTAs to target the identified unmet needs in patients with psoriasis. The 13 CTAs were developed by three key stakeholder types: clinicians (dermatologists), payors and patients, and were categorised across eight themes: (1) improve healthcare systems to better support multidisciplinary team (MDT) working and digital services, (2) real-world data generation and optimal use, (3) improve patient access, (4) elevate quality of life measures as the most important outcomes, (5) involve patients in patient-centred care and personalised approaches to care, (6) improve relevance and reach of guidelines, (7) education, (8) multi-stakeholder engagement [1].

This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

At present, materials from the Epicensus programme designed to mediate further conversations at national levels are being utilised in

France, propagating the strategic implementation of CTAs.

Capitalising on the benefits of digital innovation has led to several initiatives such as the transition of patient records onto robust electronic patient databases at national and local levels. For example, transfer of handwritten patient notes into electronic files is ongoing and is being actively supported by hospital authorities and the healthcare technology solutions company IQVIA Greece, whilst the inclusion of critical disease severity tools in the national database for patients on biologics has been fully implemented in Denmark. The relevance of the CTAs outlined in our original publication can also be demonstrated in a number of alliances and initiatives in Italy, including the ongoing development of a digital care programme which is dedicated to creating durable and collaborative approaches to patient care [2]. The deployment of effective digital tools will improve the monitoring of patient outcomes and enhance MDT care pathways. Additionally, the strengthening of MDT working is at the forefront in Germany, as the Regional Psoriasis Networks Germany PsONet has now expanded across 31 regional care networks which cover more than 90% of the country and follow shared national health care goals for psoriasis.

Independent multistakeholder activities which align with key concepts highlighted in our CTAs are ongoing. As it stands, a recent update of the German S3 guideline [3] (supported by key German dermatology networks such as PsONet Germany, The Professional Association of German Dermatologists (BVDD), The German Society for Dermatology (DDG) and Hautnetz) has now been transformed to a patient guideline for the treatment of psoriasis. Moreover, a pilot project to encourage patient participation in clinical trials is underway in Denmark in a partnership between government and patient organisations [4]. We also note that in Italy the patient voice is being amplified through alliances between patient organisations and dermatology societies as part of formal chronicity planning.

Education is key in the elevation of the SoC in patients with psoriasis. Webinars, conferences

and preceptorships in psoriatic disease have been completed or are in progress at a national, European and local level. On 22 March 2023, a webinar was held in partnership with Epidermia, a Panhellenic association of patients with psoriasis, to inform and educate patients on psoriasis and the associated risk of cardiovascular disease. This webinar amassed an audience of 9056 attendees, covering key topics such as identifying risk factors of cardiovascular disease and how preventative measures can be implemented. Materials are available on-demand, facilitating flexible patient-learning. Further to this, development of educational activities is underway where focus has been placed on tackling the stigma in visible chronic skin conditions. This can be demonstrated through Acción Psoriasis, a patient association in Spain, and their involvement in the development of an educational video highlighting that the anxiety and depression experienced by people with psoriasis is often borne from lack of knowledge of the disease and assumptions held by many [5]. The psychological impact of psoriasis was duly highlighted during the Epicensus programme, as concerns pertaining to the availability of appropriate monitoring practices were raised.

We hope that the Epicensus programme continues to inspire multiple stakeholders to collaborate on critical initiatives. Continued efforts are needed to elevate the SoC for patients with psoriasis, allowing patients to experience improved quality care.

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Declarations

Conflict of Interest. Simon Francis Thomsen has received research support from Janssen, LEO Pharma, Novartis and UCB; and has served on advisory boards for Almirall, Eli Lilly, Galderma, Incyte, Janssen, LEO Pharma, Novartis, Pfizer, UCB, Union Pharmaceuticals; and as a speaker for LEO Pharma, Novartis, Symphogen and UCB and has been the recipient of a travel grant to GUF and EADV from Novartis. Valeria Corazza has no other conflicts of interest to declare. Matthias Augustin has received consulting fees from AbbVie, Almirall, Amgen, Biogen, Boehringer Ingelheim, Celgene, Centocor, Eli Lilly, GSK, Hexal, Janssen, LEO Pharma, Medac, Merck, MSD, Mundipharma, Novartis, Pfizer, Sandoz, UCB Pharma and Xenoport. Elizabeth Lazaridou has received research grants to her department from AbbVie, Genesis Pharma, Janssen, LEO, Lilly, Novartis, Pfizer and UCB; honoraria for activities such as lectures/presentations/speaker bureaus from AbbVie, Genesis Pharma, Janssen, LEO, Lilly, Novartis and UCB; support for attending meetings and/or travel from AbbVie, Janssen, LEO, Lilly and UCB; and has participated on a Data Safety Monitoring Board or Advisory Board for AbbVie, Genesis Pharma, Janssen, LEO, Lilly, Novartis, Pfizer and UCB. Lluís Puig has received grants/support paid to his institution from AbbVie, Almirall, Amgen, Boehringer Ingelheim, LEO Pharma, Lilly, Novartis, Pfizer, Sanofi and UCB; consulting fees from AbbVie, Almirall, Amgen, Boehringer

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Ethical Approval. This article is based on previously conducted studies and does not contain any new studies with human participants or animals performed by any of the authors.

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REFERENCES

1. Koren J, et al. Elevating the standard of care for patients with psoriasis: 'calls to action' from epicensus, a multistakeholder pan-European initiative. *Dermatol Ther.* 2023;13:245–68.
2. Digital Health. Digital Care Program, the first telemedicine solution for psoriasis. 2022. <https://www.digitalworlditalia.it/digitalhealth/terapia/telemedicina/digital-care-program-telemedicina-per-la-psoriasis-152695>. Accessed 05 Mar 2024
3. Nast A, et al. German S3-Guideline on the treatment of psoriasis vulgaris, adapted from EuroGuiDerm - Part 1: treatment goals and

-
- treatment recommendations. *J Dtsch Dermatol Ges.* 2021;19(6):934–150.
4. Healthcare Denmark. Decentralised clinical trials in Denmark. 2022. <https://healthcaredenmark.dk/national-strongholds/innovation/decentralised-clinical-trials/>. Accessed 05 Mar 2024
 5. Psoriasis Action. Have you ever shared a car with strangers? 2023. <https://accionpsoriasis.org/enladi-reccioncorrecta/>. Accessed 05 Mar 2024.