

RE-ENGAGING THE SILENT:

CHALLENGES OF PATIENT ENGAGEMENT IN ATOPIC DERMATITIS

Hannah Brown & Elizabeth Baynton
Ipsos Global Autoimmune Therapy Monitors
October 2020



RE-ENGAGING THE SILENT:

CHALLENGES OF PATIENT ENGAGEMENT IN ATOPIC DERMATITIS

Hannah Brown & Elizabeth Baynton
Ipsos Global Autoimmune Therapy Monitors
October 2020

Introduction: Stepping out of the background

Despite the relatively high incidence of atopic dermatitis (an estimated 20% among children and 7–14% among adults in Europe & USA ^[1]), lack of targeted therapeutic options and low public awareness of the disease contribute to negative patient experiences. Whilst the condition has plagued both developed and developing countries for a very long time, it is only truly in the last few years that atopic dermatitis (AD) has gained traction and recognition outside of those who suffer from it. This is evidenced by the recent introduction of World AD Day in 2018, aimed at building global awareness and acknowledgement of the struggles of those living with AD. The momentum must continue to build in order for AD to achieve the same level of awareness as that of many other chronic conditions but, for the first time in a long time, people with AD are starting to see a change in the way their condition is treated and managed ^[2].

Historically, the standard of care for treating AD was limited to treatments not focused on the pathogenesis of the disease. Then, Sanofi-Regeneron's dupilumab, a targeted biologic therapy approved by the FDA in March 2017 ^[1] for moderate to severe patients, paved the way for a new era in systemic AD treatment. Dupilumab is soon to have company. Today, a number of advanced targeted therapies are in development and due to enter the market in the coming years. The availability of these treatments is sure to change the AD space, bringing new and alternative options for patients suffering with moderate-severe forms of the condition.

In recent years, the medical and scientific communities have placed growing emphasis on the assessment of the quality-of-life impact of living with a chronic condition ^[3]. This is increasingly incorporated as an important clinical marker of note and trial endpoint. In the case of atopic dermatitis, the new treatment options – informed by a better understanding of the disease pathology – hold the promise of addressing the burden of itch and reduced sleep that AD patients are all too familiar with.

To better understand the AD patient-physician dynamic and identify opportunities to optimise patient outcomes and highlight potential points of engagement, we draw on insights from Ipsos' Syndicated Atopic Dermatitis Patient and Caregiver Communities in the EU5 and Canada, in conjunction with physician feedback from Ipsos' Syndicated Atopic Dermatitis Therapy Monitor (see 'About the Research' for details).

The undesired influencer: I have as much control as my skin allows

As a condition characterised by periods of remission and relapse, it is no surprise that lack of control is a well-documented aspect of living with AD [4]. This is verified with insights from Ipsos’ AD Patient Community, an online qualitative community of patients with moderate-severe forms of atopic dermatitis in the EU5 and Canada.

While personal experiences of AD differ, many patients participating in the Community tell of the unpredictable nature of AD and a life dictated by their skin. Individual participants have described being unable to dress as they wish, eat what they like or partake in the activities they want to. Whilst in many ways this may be influenced by the allergic component and aetiology of the condition itself – in other words, the need to avoid triggers at all costs – there is no denying that some Ipsos Community patients confer a degree of blame on the outside world, from which many go to great lengths to hide their condition. In open conversations with participants, we have heard patients describe feelings of being judged by the sores on their skin, being exposed to unsolicited opinions from others and the indefatigable question, “have you tried...?”. Whilst good days reportedly brought periods of normality and flexibility, bad days saw many submit to their condition and their desire to hide away from the world. The desire for normality that we observed in this study is a typical goal for many living with a relapsing chronic disease – but it’s one that poses a clinical challenge as the variation in each individual’s definition of ‘normal’ has important implications for measuring their level of control [5].

The figure below shows a selection of images posted by Community respondents to depict their mood. Representations of isolation, shame and mental exhaustion are prominent, albeit there is an indication of hope for the future.

Figure 1: Mood board image representation of images moderate-severe AD patients posted about their condition (NB: images have been replaced in order to respect respondent confidentiality whilst retaining sentiments expressed).



Ipsos EU5 & Canada AD Patient Community, May 2020 (~150 patients (~25 in UK, France, Germany, Italy, Spain & Canada) with moderate-severe AD, participating in a qualitative research community moderated by Ipsos’ AD specialists who conduct group and individual activities over time. Patients are screened to ensure a Community that reflects patients taking a range of prescription therapies for their AD with varying time since diagnosis.)

With this said, Community findings suggest that negative patient attitudes towards living with AD may not always be present at the onset of their condition. The figure below summarises key takeaways from an exercise in which respondents were asked to write a letter to their condition. For most, life with AD is not how they pictured it at the beginning. What was once perceived as a temporary diagnosis, dismissed by some patients as a 'one-time thing', has now rooted itself in all areas of their lives as the burden of alterations to their appearance has become harder to bear. Over time many have come to experience less autonomy, a drop in confidence and a realisation that AD is here to stay.

Figure 2: Qualitative summary of a letter moderate-severe AD patients wrote to their condition



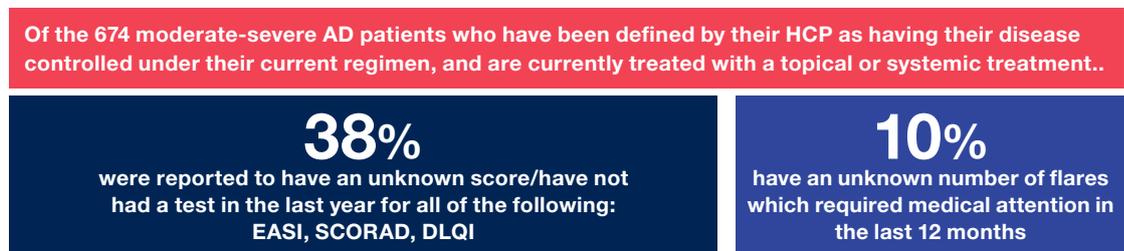
Minor alterations have been made to verbatim comments to respect respondent confidentiality, whilst retaining sentiments expressed

Ipsos EU5 & Canada AD Patient Community, May 2020 (~150 patients (~25 in UK, France, Germany, Italy, Spain & Canada) with moderate-severe AD, participating in a qualitative research community moderated by Ipsos' AD specialists who conduct group and individual activities over time. Patients are screened to ensure a Community that reflects patients taking a range of prescription therapies for their AD with varying time since diagnosis.)

How well do physicians know their AD patients?

Data from Ipsos' Syndicated Atopic Dermatitis Therapy Monitor, based on 210 dermatologists providing real-world data on AD patients treated between May-July 2020 (see 'About the Research' for full details of the methodology), suggests a potential disparity in ascertaining disease control when evaluating treatment efficacy. 66% of moderate-severe AD patients reported on by Ipsos' sampled physicians are considered 'controlled' under their current treatment regimen (by physician interpretation). However, taking the proportion of the reported 'controlled' patient sample who continue to experience a flare, together with the aforementioned patient feedback on their experiences, suggests a degree of subjectivity on the part of the physician.

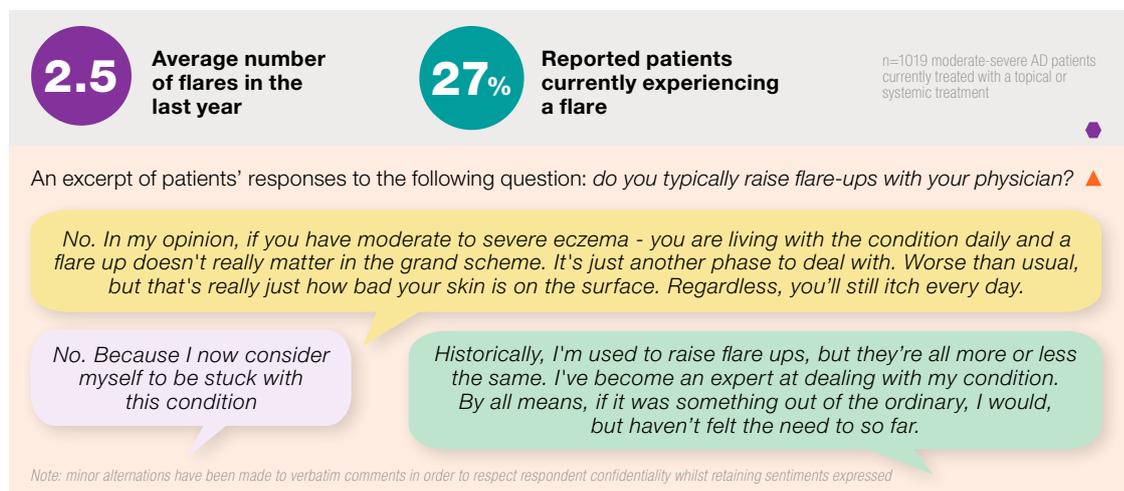
Figure 3: Understanding use of clinical tests within those considered to have ‘controlled’ AD by physician interpretation



Note: these are the three most widely used tests captured in the study
 N = all moderate-severe AD patients currently treated with a topical or systemic treatment who are considered ‘controlled’ under their current regimen by HCP interpretation
 Source: Ipsos EU5 AD Monitor (May - July 2020, ~210 dermatologists reporting on moderate-severe AD patients seen in consultation (~42 in UK, France, Germany, Italy & Spain; total EU5 % is an unweighted total of the participating countries). Physicians were screened for duration of practice/patient volume. All data were collected online.) © Ipsos 2020. All rights reserved

Additional challenges for consideration in quantifying this potentially subjective parameter are apparent when evaluating clinical testing in the reported patient sample. 38% of moderate-severe patients reported on by sampled physicians in the Therapy Monitor present with either an unknown score or have not had a test in the last year for the three most widely used parameters captured in our study: EASI, DLQI and SCORAD (see ‘About the Research’ for disease score explanation). Use here is typically adopted in those reported patients at the most severe end of the spectrum, who are already treated with a biologic, and hence the potential opportunity for missed candidates for targeted therapy presents. Further challenges rear their head from the patient side as findings from our Community study highlight patients’ hesitancy in raising flare-ups and symptoms with their medical team unless they simply can’t manage them. Cases where this conversation is more likely to occur are when the current prescription is not strong enough to curb the symptoms, or where the flare-up they’re facing is something different to the usual – in which case they’d seek medical advice.

Figure 4: Reported flare experience and attitude towards raising flares in moderate-severe AD patients



● Source: Ipsos EU5 AD Monitor (May - July 2020, ~210 dermatologists reporting on moderate-severe AD patients seen in consultation (~42 in UK, France, Germany, Italy & Spain; total EU5 % is an unweighted total of the participating countries). Physicians were screened for duration of practice/patient volume. All data were collected online.) © Ipsos 2020. All rights reserved
 ▲ Source: Ipsos EU5 & Canada AD Patient Community, May 2020 (~150 patients (~25 in UK, France, Germany, Italy, Spain & Canada) with moderate-severe AD, participating in a qualitative research community moderated by Ipsos’ AD specialists who conduct group and individual activities over time. Patients are screened to ensure a Community that reflects patients taking a range of prescription therapies for their AD with varying time since diagnosis.)

What lies behind these internalised concerns is illustrated by patient recall of the actual and ideal conversations in the figure below. When voicing concerns and attempting to detail symptoms and flare-ups, several patients participating in the Community commented that their remarks are often batted away during conversations with their physician and met with comments such as ‘nothing we can do’, ‘it’s just part and parcel of the condition’ – suggesting room for improvement in physician-patient communication. For those Community participants most impacted by the relationship breakdown, responses suggest considerable mistrust towards the medical profession. Examples of responses from participants regarding what they would be thinking, but not saying at a typical consultation with their physician include: *“lack of investment in my wellbeing”, “this justifies my distrust towards the medical profession”, “I’ve already tried that, it did not yield any benefit”* and *“great, the least effort possible to find a solution to this ongoing issue”*. (Minor alterations have been made to verbatim comments in order to respect respondent confidentiality, whilst retaining sentiments expressed).

Figure 5: Patient interpretation of actual vs ideal conversations with their physician when raising a concern regarding symptom breakthrough on their current treatment regimen



Source: Ipsos EU5 & Canada AD Patient Community, May 2020 (~150 patients (~25 in UK, France, Germany, Italy, Spain & Canada) with moderate-severe AD, participating in a qualitative research community moderated by Ipsos' AD specialists who conduct group and individual activities over time. Patients are screened to ensure a Community that reflects patients taking a range of prescription therapies for their AD with varying time since diagnosis.)

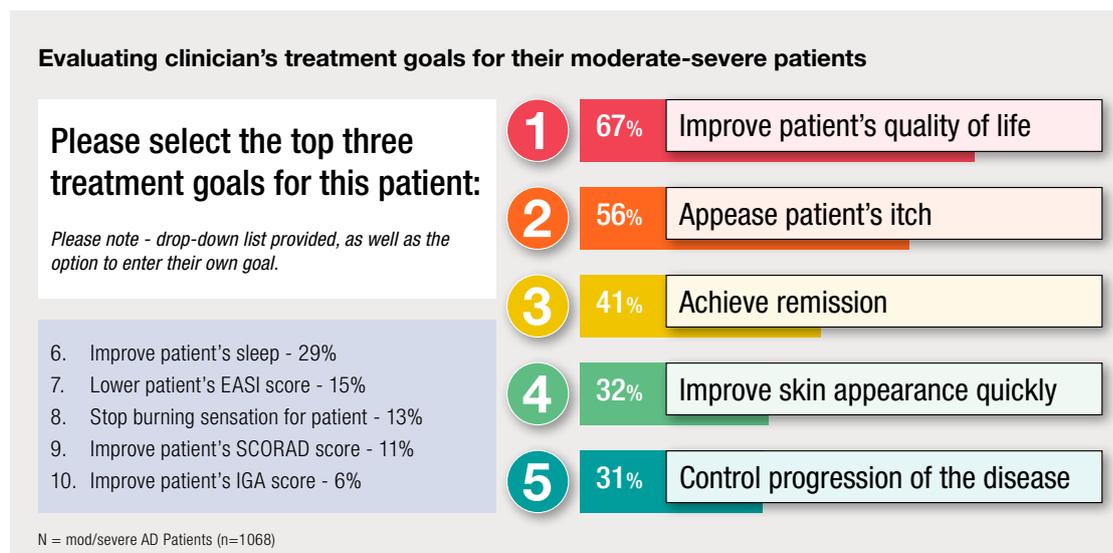
Whilst some Community patients' perception of the patient-physician interaction suggests room for improvement, in our opinion the therapeutic landscape for AD has been restrictive for physicians too. Patient Community participants express frustrations with the lack of a plan, yet physicians have simply not had the tools at their disposal to treat AD in the way they have for other dermatological conditions, such as psoriasis, where targeted therapeutics have been available for use since 2004 [6]. Additionally, of late, disruption from the COVID-19 pandemic may have further contributed to the disconnect. 88% of sampled dermatologists

who participated in the AD Therapy Monitor report seeing fewer patients in the last month as a result of COVID-19 and, with the growing adoption of telemedicine over face to face interactions, it may prove more and more challenging for physicians to build that relationship. As empathy and clear communication present as a proxy indicator of physicians' competence and skill [7], undoubtedly how patients feel about the interaction is a fundamental point of consideration when looking towards future patient engagement in the AD arena.

Less talk, more action

As Patient Community insights highlight the day to day struggle of living with and adapting to life with AD, it is no surprise that 'quality of life' ranks as the top treatment goal for sampled physicians participating in the AD Therapy Monitor, illustrated in the figure below. *Appeasing itch* and *achieving remission* were also frequently mentioned, with reference to specific clinical measures (EASI, SCORAD and IGA scores) far less frequently noted. When analysing treatment patterns among reported moderate-severe AD patients by physician goal, treatment usage is fairly consistent across the board – between 44% and 47% of reported moderate-severe patients are treated with a topical therapy, regardless of the goal outlined by their physician on the patient record form. In our view, this goes some way to suggest that goals do not, or cannot, necessarily translate into prescribing habits. It will be prudent to monitor this in future waves of our study to see if the upcoming market entrants and greater options available have a ripple effect on the way AD is treated in our sample, and why.

Figure 6: Evaluating physicians' treatment goals for their moderate-severe AD patients

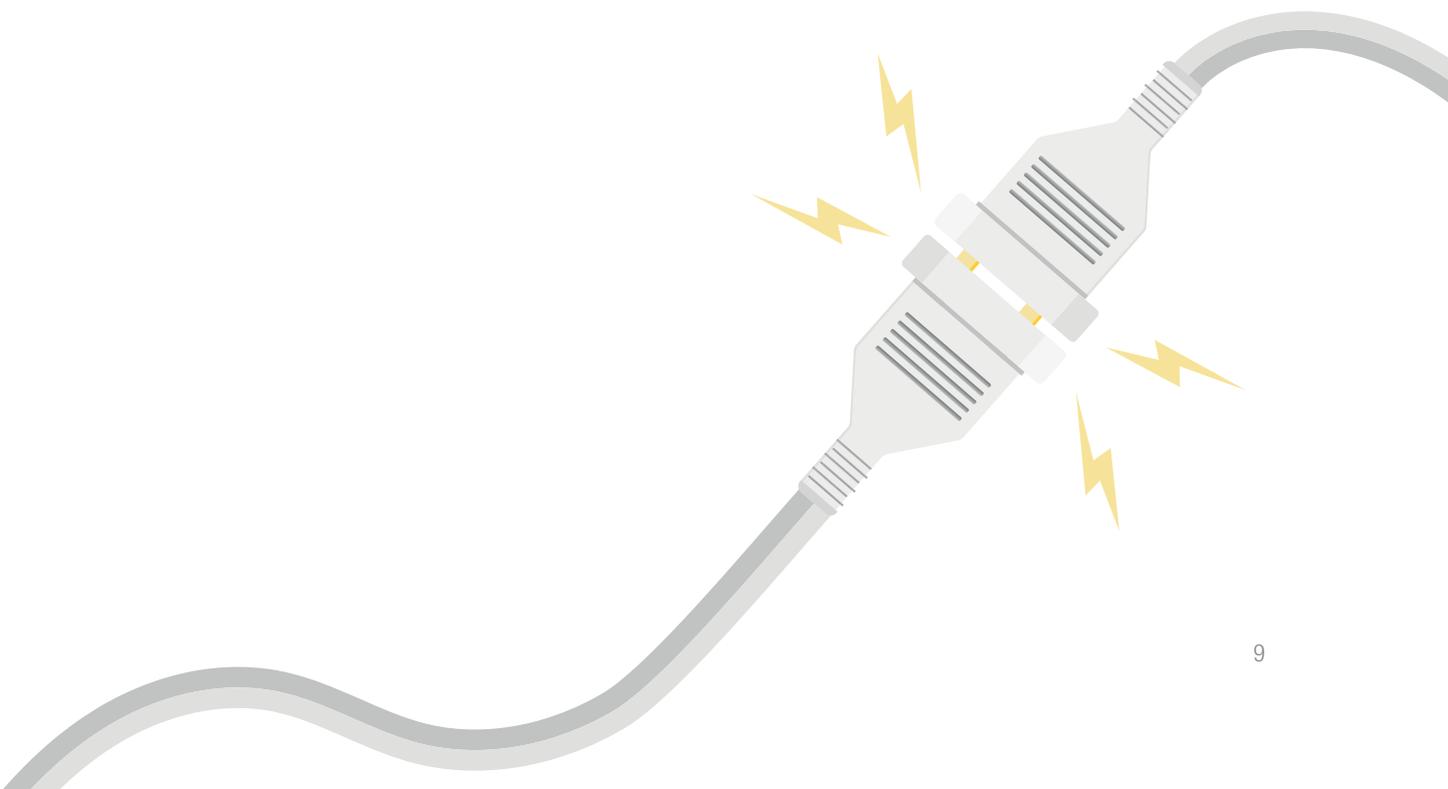


Source: Ipsos EU5 AD Monitor (May - July 2020, ~210 dermatologists reporting on moderate-severe AD patients seen in consultation (~42 in UK, France, Germany, Italy & Spain; total EU5 % is an unweighted total of the participating countries). Physicians were screened for duration of practice/patient volume. All data were collected online.) © Ipsos 2020. All rights reserved

The apparent disconnect between treatment goals in the minds of sampled physicians, and the associated reported prescribing in the AD patient sample, is corroborated by some of the Patient Community feedback gleaned on treatment consultations. Many were of the opinion that they were being prescribed treatments without a true explanation of why, further reinforcing the impact of physicians operating with sub-satisfactory options.

Future Outlook:

While it is undoubtedly an exciting time in the atopic dermatitis therapy space for physicians and patients alike, the points raised in this paper suggest the need to raise the patient voice in order to optimise their engagement in future treatment plans. Whilst on face value the imminent expansion in treatment options is beneficial to both patients and physicians, the conversation between the two parties may need to be reframed in order to ensure information exchange is optimally fuelling treatment decisions. On the part of patients, a long-standing tendency of some to ‘hide’ their condition, coupled with a potential disconnect with HCPs, are key obstacles for consideration. On the part of physicians, a history of typically only having access to non-targeted therapies for their AD patients will now be subject to change. As these new treatment options enter the fray, making sure that news of their availability permeates appropriately throughout both the physician and patient communities, as well as ensuring physicians are extracting enough information from their patients to accurately identify potential candidates for these options, are important considerations for pharma going forward. Optimising these relationships will help ensure access to the most effective treatments, and improve the lives of those living with AD.



About the Research:

Ipsos' Syndicated Atopic Dermatitis Patient Community (May 2020, ~150 patients (~25 in UK, France, Germany, Italy, Spain & Canada) is an online qualitative research community of moderate-severe Atopic Dermatitis patients in the EU5 and Canada who chose to participate. Patients are screened to ensure a Community that reflects patients taking a range of prescription therapies for their AD with varying time since diagnosis. The Community is moderated by Ipsos' AD specialists who conduct group and individual activities over time.

Patients' clinical demographics and prescribing patterns were investigated using EU5 data from the Ipsos Global Atopic Dermatitis Therapy Monitor. The Ipsos Global Atopic Dermatitis Therapy Monitor is a physician-reported syndicated patient record database, capturing prescribing of both topical and drug treatments in AD. Participating physicians are required to treat a minimum number of AD patients in a typical quarter and be the primary decision-maker for their patients. Each wave, participants provide demographic information, de-identified information on a predefined quota of patients seen prospectively (Patient Record Form). Data used in this article were provided by 210 dermatologists in EU5 (~42 in UK, France, Germany, Italy and Spain), reporting on 1068 moderate-severe AD patients seen in consultation between May-July 2020. Data were collected online.

The following abbreviations were utilised to summarise the clinical assessment scores reported on in the research; EASI: Eczema Area and Severity Index; DLQI: Dermatology Life Quality Index; SCORAD: Scoring Atopic Dermatitis.

Data are © Ipsos 2020, all rights reserved.

References:

- [1] Bylund, S., Von Kobyletzki, L., Svalstedt, M. and Svensson, A. Prevalence and Incidence of Atopic Dermatitis: A Systematic Review, *Acta Derm Venereol.* 2020; 100:adv00160.
- [2] Sugita, K. and Akdis, C. Recent developments and advances in atopic dermatitis and food allergy, *Allergology International.* 2020; 62(2): 204-214.
- [3] Shofany, C. Quality of life among chronic disease patients, *Nursing and Care Open Access Journal.* 2017; 4(2): 385-394.
- [4] Simpson, E. et al. Validation of the Atopic Dermatitis Control Tool (ADCT ©) using a longitudinal survey of biologic-treated patients with atopic dermatitis, *BMC Dermatology.* 2019; 19(15).
- [5] Howells, L., Chalmers, J., Cowdell, F., Ratib, S., Santer, M. and Thomas, K. 'When it goes back to my normal I suppose': a qualitative study using online focus groups to explore perceptions of 'control' among people with eczema and parents of children with eczema in the UK, *BMJ Open.* 2017; 7:e017731.
- [6] Thomson, A. Etanercept in psoriasis: the evidence of its therapeutic impact, *Core Evid.* 2007; 2(1):51-62.
- [7] The BMJ. 2020. Has the covid-19 pandemic changed the doctor-patient relationship forever? - The BMJ. [ONLINE] Available at: <https://blogs.bmj.com/bmj/2020/06/08/has-the-covid-19-pandemic-changed-the-doctor-patient-relationship-forever/>. [Accessed 19 October 2020].

About Ipsos' Healthcare Service Line

Ipsos partners with pharmaceutical, biotech and medical device manufacturers to inspire better healthcare. Operating in over 50 countries, our 1000+ experts support key business decisions for our clients throughout the commercial lifecycle, from early-stage strategy, to launch, to performance optimization. We do this through a uniquely integrated combination of therapeutic and market expertise, gold standard real world evidence, and market-leading custom research approaches – all underpinned by a global footprint and unprecedented access to today's healthcare stakeholders.



www.ipsos.com