

ECOO NEWS

Building Trust in Digital Health: ECOO's Contribution to the eHealth Stakeholder Group

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Summary

ECOO was part of the European Commission's eHealth Stakeholder Group (eHSG) for six years, an advisory body shaping EU digital health policy:

- *ECOO helped make patient trust and data protection central to EU digital health and the European Health Data Space.*
- *ECOO pushed back against treating health data as a commodity, leading to stronger safeguards on data use.*
- *After the eHSG ended in 2026, ECOO is preparing to engage through new EU AI and health data forums.*

The eHealth Stakeholder Group (eHSG) is an advisory body established by the European Commission in 2012 to support the development and implementation of eHealth policies and initiatives across the European Union. The group is led jointly by the Directorate-General for Communications Networks, Content

and Technology (DG CNECT) and the Directorate-General for Health and Food Safety (DG SANTE). The eHSG was relaunched in 2020 and held its first meeting on 13 July that year.

ECOO's Role in the eHealth Stakeholder Group

ECOO has been a member of the eHSG for the past six years. During this period, the group has held 12 plenary meetings and 10 webinars covering a wide range of digital health topics. In addition to these formal meetings, several optional meetings, spin-off sessions and smaller working groups were organised, enabling more focused collaboration between members on specific themes and initiatives.

The twelfth and final meeting of the eHSG took place on 22 January 2026.

When ECOO first joined the eHSG, the work felt like hot liquid lava rising from the ground — fascinating and frightening at the same time. Much

of the early effort was spent on understanding, following and attempting to influence a rapidly developing agenda. At that time, the European Union was pushing for high speed and minimal obstacles in the development of future digital healthcare systems.

ECOO was the only organisation representing eye health within this work, alongside a broad range of other healthcare professions and patient interest groups. In the early stages, there was limited attention paid to patient trust and to the potential negative consequences of handling health data from across Europe on large digital platforms. This raised concern, particularly given the scale and sensitivity of the data involved.

Embedding Trust in the European Health Data Space

Within a short period, other organisations, including the European Public Health Alliance (EPHA) and the Standing Committee of European Doctors (CPME), also began to highlight the risks of undermining patient trust. Today, trust between patients and the healthcare system has become a core value in the future development of the European Health Data Space (EHDS) and related initiatives.

A wide range of topics have been discussed within the eHSG. ECOO has been particularly engaged in general digital development and in the establishment of the EHDS. The

concept of “trust” now appears repeatedly in documentation and discussions related to the EHDS, underlining its fundamental importance to the relationship between patients and healthcare practitioners.

Within the regulation of the EHDS, there are clear traces of ECOO’s influence, particularly regarding the secondary use of health data. ECOO helped make the European Union aware that most health data are highly sensitive and should not be treated as commodities for free and open sale, as was initially envisaged in the early stages of the EHDS process. As a result, such data are now better protected and their distribution more strictly limited.

ECOO has invested considerable effort in informing its members at their spring and autumn General Assembly meetings. ECOO committees have issued a [joint statement on digital development](#) and ECOO has delivered presentations and participated in debates on digital health in several European countries. In addition, an article entitled “[Moving forward with the European health data space: the need to restore trust in European health systems](#)” was published in *The Lancet* in collaboration with EPHA.

Looking Ahead: Continuing Engagement in European Digital Health

The eHSG is now history. Going forward, ECOO will need to establish

new relationships in order to understand and influence the continued development of European eHealth policies and initiatives. Some former partners from the eHSG will remain important connections. At the same time, ECOO recognises that it is a relatively small organisation and cannot manage or fully grasp all future developments on its own.

Fortunately, further opportunities for engagement are emerging. The European Commission has informed former eHSG members about the possibility of joining the Apply

Artificial Intelligence Alliance, a platform for exchanging information on artificial intelligence in health. In addition, the European Health Data Space Stakeholder Forum will be launched in 2027, with a call for expressions of interest expected before the end of 2026.

These platforms will be crucial in ensuring that patient trust, data protection and professional perspectives remain central to Europe's digital health future.

ECOO'S ACKNOWLEDGEMENT OF HANS TORVALD HAUGO'S CONTRIBUTION

ECOO wishes to express its sincere thanks to Hans Torvald Haugo for his leadership and commitment in representing the organisation within the eHealth Stakeholder Group. Over several years, he has attended numerous meetings and working sessions, consistently representing the interests of the eye health sector with professionalism, clarity and dedication.

Through his work, ECOO has played a credible role in discussions on digital health and the European Health Data Space, particularly in promoting patient trust and responsible use of health data. His contribution has strengthened ECOO's position in European health policy and ECOO is grateful for his diligent and successful work over these years.

ABOUT ECOO

The European Council of Optometry and Optics (ECOO) represents the interests of optometrists and opticians across Europe. Our members are national professional associations from 25 countries who together represent more than 200,000 opticians and optometrists. ECOO aims to promote eye health to the public across borders and to harmonise clinical and educational standards of optometric and optical practice throughout Europe.