

# Summary of Breakout Groups

“Health Data for Better Health” GlobalSkin-Europe Member Event Sept.29, 2026

## Discussions

*Patient perspectives on health data sharing and governance*

The breakout groups identified three closely connected priorities:

- building trust through transparency and data protection,
- empowering patients with meaningful control and influence over their health data,
- ensuring patient organisations are actively involved in data governance.

Across the discussions, participants emphasised that responsible health data sharing requires more than legal compliance. It must be grounded in patient trust, clear communication, meaningful participation and accountability.

## 1. What builds trust in sharing health data?

Transparency, privacy, security and clarity about how health data will be used emerged as the main foundations of trust.

Groups' conclusions:

- Transparency about data use: Patients need to understand why their data is collected, how it will be used, who will access it and who the final users or beneficiaries are.
- Privacy, confidentiality and consent: Strong data protection safeguards, respect for patient consent and compliance with relevant legislation are essential.
- Secure data storage: Patients need reassurance about the safety of their data, including where it is stored, which organisations or countries are involved, and what security measures are in place.
- Patient control and ownership: Trust depends on patients understanding their rights and having meaningful influence over the use of their data.
- Clear communication: Accessible information about data-sharing practices should reflect the full patient experience, not merely technical or legal requirements.

- Patient organisation involvement: Including patient representatives in discussions and decisions can strengthen confidence in data governance.

Key message: Trust is built when patients know what happens to their data, understand its purpose and feel confident that their rights, privacy and interests are protected.

## **2. What should patients be able to control or influence?**

Participants highlighted the importance of meaningful patient influence over access to, sharing of and use of health data.

Groups' conclusions:

- Access and sharing decisions: Patients should understand and be able to influence which data is shared, with whom, and whether sharing is complete or limited to specific information.
- Purpose of data use: Patients should know what their data is being used for and have a say in acceptable uses.
- Consent and authorisation: Clear approval mechanisms and appropriate safeguards should govern data access and secondary use.
- Data retention: Patients should be informed about and, where appropriate, influence how long their data is retained.
- Ownership and control: The roles, responsibilities and rights associated with health data ownership and control need to be clarified.
- Protection against misuse: Participants expressed concerns about inappropriate access, surveillance and uses beyond the originally communicated purpose.

Key message: Patients should not simply be passive sources of health data. They should have clear rights, accessible information and meaningful opportunities to influence decisions about its use.

## **3. How can patient organisations contribute to better data governance?**

The discussions highlighted patient organisations as essential partners in developing transparent, inclusive and patient-centred data governance.

Groups' conclusions:

- Participation in governance: Patient organisations should be directly involved in governance structures, legislative processes and shared decision-making.
- Bridging the gap: They can connect policymakers, healthcare institutions and patients by translating complex governance issues into understandable information.
- Education and engagement: Patient organisations can improve data literacy, raise awareness of patient rights and encourage informed participation.
- Representing patient concerns: They can identify patients' needs, experiences and concerns regarding data use, privacy and access.
- Policy development and feedback: Through consultations, umbrella organisations and feedback mechanisms, they can help shape and improve data governance policies.
- Supporting compliance and accountability: Their involvement can help ensure that governance frameworks reflect patient interests alongside legal and ethical obligations.
- Recognition as equal partners: Patient organisations should be accepted as legitimate partners throughout governance processes, rather than consulted only after decisions have been made.

Key message: Patient organisations should move beyond an advisory role to become recognised partners in decision-making, policy development, patient education and governance oversight.

Patient organisations must be recognised as governance partners.

Their involvement in policy development, decision-making, education and oversight helps ensure that governance reflects real patient needs and experiences.