Q&A PUBLICATION

From Engagement to Partnership:

Advancing Pharma–Patient Community Collaboration

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What makes patient-industry engagement valuable, what needs to change, and how to create the conditions for stronger collaborations – including at policy and regulatory levels? Hear the perspectives of three experts who discuss these topics and how to foster patient engagement across the healthcare ecosystem.

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What are the biggest hurdles today to patient-industry collaborations?

Kersten Sharrock: I really do not see many – collaborations are largely the norm. While conflicts of interest (COI) regulations are less than ideal - the reality is that they are not changing much. There are also clear guidelines via industry associations, like EFPIA, for active engagement with the patient community. At the end of the day, there are two realities that have meant a maintenance of the status quo: the value of engaging in drug development is proven and far outweighs the uncertain impact of patient participation in EMA or HTA (which remains inconsistent), and there are a lot of patients and multiple organisations, meaning in many disease areas the patient community can meet all these needs. In addition, larger organisations are creating 'walled off' staff to serve both the drug development process and the regulatory and HTA processes.

Ilaria Leggeri: Health challenges are too complex for any single stakeholder to solve alone, which makes patient-industry partnership essential. Across Europe, significant progress has been made towards more transparent, meaningful and mutually beneficial partnerships. As a result, today there are often more opportunities than barriers to effective collaboration.

That said, challenges remain and vary depending on the country, therapeutic area and maturity of the patient community. In some settings, concerns around transparency, COI and capacity might still create barriers. In the cardiovascular space, I would highlight maturity and resourcing as key challenges. Compared with fields such as oncology or rare diseases, many cardiovascular patient organisations are younger, smaller and/or have fewer opportunities to engage in multi-stakeholder efforts.

This is why platforms such as the EFPIA Patient Think Tank are so valuable. They provide a transparent space for patient organisations and industry to exchange perspectives, learn from each other and identify practical ways to strengthen collaboration.

Elisabeth Dupont: I think we've come a long way. Collaboration today is much more structured and transparent than it was a decade ago. But there are still three things that, to me, make the biggest difference: trust, capacity and timing.

Trust is built through openness, clear expectations and respect for each partner's role. Patient organisations need to remain independent, and good governance should make collaboration easier, not more difficult.

Capacity is another challenge. Patient organisations are being asked to contribute to an increasing number of projects with limited resources. Meaningful involvement takes time, preparation and investment from everyone involved.

Finally, timing matters. The greatest value comes when people living with diabetes are involved while priorities and solutions are still being shaped up – not once the key decisions have already been made.

What do you value from a company/a patient group when working together?

Kersten Sharrock: The same things you value from any partnerships - transparency, trust, active engagement, focus on outcomes and impact.

Ilaria Leggeri: For me, good collaboration starts with active listening, openness to learn and attention to creating an environment where questions can be asked, expectations are transparent and feedback goes both ways. I really value it when patient groups feel comfortable being candid - telling me what works for them, what doesn't, what aligns with their priorities and where we could do better. I would always rather hear what patients and patient organisations truly think than what they believe industry wants to hear.

Elisabeth Dupont: For us at IDF Europe, the best partnerships are built on trust, transparency, mutual respect and a shared commitment to ultimately improving the lives of people living with diabetes.

We value companies that recognise patient organisations as independent partners and genuinely understand the role we play by bringing together lived experience and perspectives from across our community and translating them into representative, evidence-informed positions that can help shape research, policy and innovation.

We also appreciate companies that see the value of working together over time. Building a strong patient community doesn't happen through individual projects alone. It requires sustained efforts – supporting future advocates, deepening policy expertise and creating opportunities for people living with diabetes to contribute where their experience can make the greatest difference.

Are there examples of collaborations that you are particularly proud of or see as good practice?

Kersten Sharrock: We partner across the full lifecycle in several ways, but the collaborations I really appreciate are around either science or change. Science in terms of informing our clinical trial protocols, shaping our outcome measures and ultimately our labels. Also science in terms of generating patient experience data that can provide context and insight to help make crucial decisions within our company and within government/policy. Projects focused on change can do things like build registries, enact screening laws, or update treatment protocols to reflect patient priorities. All these examples put patients in the driver's seat in a more meaningful way.

Ilaria Leggeri: I am particularly proud of collaborations that involve patient organisations early and meaningfully, with a genuine commitment to co-creation. One example is a project we developed together with the Atrial Fibrillation Association to better understand what quality of life means to people living with atrial fibrillation.

Elisabeth Dupont: Looking back, the collaborations I'm most proud of are those that have reinforced the diabetes community over the long term.

The most successful partnerships are those that recognised the importance of investing in building the capacity of the patient community itself. This has been, and continues to be, instrumental in supporting the next generation of diabetes advocates, fostering our engagement with people living with diabetes, developing evidence-informed policy positions, and ensuring that the voices of our national member associations are reflected in European research and policy discussions.

What makes these collaborations successful is the mutual respect for each other's roles, combined with open and regular dialogue. They enhance our ability to collaborate without compromising our independence. For me, that's the hallmark of a good partnership – it leaves patient organisations stronger, more representative and better equipped to advocate for the people they serve.

What KPIs best measure meaningful patient engagement today?

Kersten Sharrock: We track a lot of numbers; and these matter. How deeply and completely are you engaging? Do you take action after insights? Do you let partnerships drive strategy and/or change your corporate direction? Monitoring and reporting on these things can really characterize the impact of the patient community, and it can also act as a roadmap for others who might not be doing as much within their organisations.

Ilaria Leggeri: This is the million-dollar question in patient engagement right now. While there has been a lot of progress, I'm not sure there is yet a universal consensus on what "best" looks like.

For me, one of the key questions is whether "traditional" KPIs are the right lens at all. Metrics often come from a commercial or operational mindset and can risk reducing patient engagement to a box-ticking exercise – like number of patients consulted, or projects completed. Those metrics may measure activity, but not necessarily quality, trust, influence, or long-term impact.

Reflecting on concepts like "return on impact" or "return on relationships" can be useful: early involvement of patients rather than late-stage consultation, diversity and representativeness of patient voices, transparency of engagement, and evidence that patient input led to tangible changes in strategy, research, care design or policy.

In my view, the future is not about choosing between quantitative and qualitative measures but mindfully combining both – measuring not only what we did, but also why, how and whether it made a difference.

Elisabeth Dupont: Counting meetings or the number of people involved tells us very little about whether engagement has made a difference.

The more meaningful questions are: Were people involved early enough to co-create rather than simply contribute? Could they influence outcomes – whether in policy, research or other areas? Were they engaged on issues that mattered to them, rather than only responding to the priorities of others?

Ultimately, meaningful engagement should be judged by the difference it makes to people's lives.

Recent regulatory changes aim to strengthen patient involvement in health and medicines decision-making. What other policy, regulatory or collective action could help?

Kersten Sharrock: Better understanding and weighing of patient experience data - both PED developed by sponsors and PED generated by the patient community. Currently it's not clear how (or if) this important context and data is considered.

Ilaria Leggeri: Developments such as the voting rights for patient representatives at EMA CHMP are important because they signal a broader cultural shift: recognising patients not simply as recipients of care, but as experts and partners in healthcare decision-making. Another example in the right direction is the EU HTA Regulation, which creates more structured opportunities for patient involvement.

For this shift to translate into truly impactful involvement, engagement needs to become systematic rather than sporadic, and patients need the right support and recognition to contribute effectively. The goal is for the patient voice to be valued not only for lived experience, but also and importantly for the essential expertise and insights it brings into healthcare decision-making.

Elisabeth Dupont: The EMA changes are an important step because they recognise that people living with a condition bring expertise that complements scientific and clinical knowledge.

Looking ahead, I'd like to see that principle applied much more consistently. By default, new health legislation should include people with lived experience and patient organisations within its governance structures, not only as consultees.

That is why, for example, we've proposed amendments to both the Biotech Act and the Medical Device Regulation to solidify patient representation in decision-making bodies. Meaningful involvement should become the norm across EU health legislation, supported by practical measures—such as training, reimbursement and administrative support—that enable patient organisations to participate effectively.

How can we enhance multi-stakeholder collaboration in patient engagement, beyond industry-patient partnerships?

Kersten Sharrock: We have big challenges facing healthcare ecosystems - they don't work as well as they need to. To tackle change and modernization in a meaningful way, it will take more than just two of the many stakeholders to be at the table.

Ilaria Leggeri: To enhance multi-stakeholder collaboration in patient engagement beyond traditional industry-patient partnerships, we should build on successful models that bring together patients, healthcare professionals, academia, regulators, payers, and industry around shared goals. European collaborative initiatives, such as Innovative Health Initiative (IHI) projects and other EU-funded programmes, demonstrate the value of co-creation, shared governance, and mutual learning. Similarly, alliances such as EACH (European Alliance for CV Health) provide impactful platforms for cross-sector dialogue and action.

These initiatives show how meaningful collaboration across sectors and borders can be fostered and scaled, enabling patient-centred solutions that evolve alongside emerging healthcare priorities and societal needs.

Elisabeth Dupont: Diabetes is far too complex for any organisation or sector to address alone. One of the things I've learned through my work at IDF Europe is that the strongest solutions come from recognising the complementary strengths that different stakeholders bring. No single organisation has all the answers. Real progress comes from respecting those different perspectives and bringing them together around a shared purpose.

For me, that is what meaningful collaboration looks like. It isn't about everyone agreeing on everything; it's about recognising the value of different perspectives and using them to build better solutions together. In many ways, it's about creating a united voice from our diversity – all with the shared goal of improving lives.

This publication is part of a DGA series about patient engagement.