

The Patient Access Partnership (PACT)

A renewed, focussed approach to maximise impact and resonance over the next 5 years

Background

As the new political mandate and the new decade begin, it is timely and necessary to revisit the raison d'être of the Patient Access Partnership (PACT) and define carefully key goals for the coming 5 years to ensure that it delivers on its vision and its mission.

Established in 2014, its main successes of the last few years can be summarised as follows:

- Bringing together, for the first time, on an equal footing, public health associations, healthcare professionals associations, industry associations in a patient led and focused partnership for a common goal and establishing itself as a 'go to' organisation on equitable access for the EU institutions;
- Ensuring that patient access to equitable, high quality healthcare is high on the political agenda, through an active EP interest group and regular meetings in the European Parliament, effective liaison with relevant officials with DG Santé and other DGs on occasions, other Institutions such as WHO and OECD, and the EU Presidencies;
- Defining the 5 'A's of access as a framework for mapping and measuring access and co-creating the EP Pilot project on the latter;
- Nurturing meaningful dialogue and partnerships at national level on the topic of patient access, using strategically instruments such as the European Semester process and the country specific recommendations. National level round tables have taken place in Bulgaria, Lithuania, Portugal and Romania;
- Through high level Conferences, setting equity of access in a wider political environment – advancing the UN Sustainable Development Goals in an EU context, promoting intersectoral collaboration on health, the economy of well-being, and indeed ensuring the future of effective health policy at EU level, with appropriate political leadership and resourcing;
- As a result of its conference on [“The Future of Health in the EU: Advancing the UN 2030 Sustainable Development agenda in Europe”](#)¹, [“The Health PACT”](#)² consensus document was developed, acknowledging successful policy coordination efforts, such as the European Pillar of Social Rights, the European Semester Process and political focus on the SDGs. Achieving this consensus across a range of health stakeholders was the culmination of the collaborative efforts of PACT during its formative years.

It could be argued that in some of our recent endeavours, albeit highly successful, our calls for actions and statements have become much more generic in nature. This, at a time when many other platforms and consortia are advancing similar wide agendas.

This collective effort was very much needed during a period of uncertainty regarding the future of health at EU level, however, now the time has come for PACT to assess carefully its specific

¹ See the main outcomes of the conference [here](#)

² [The Health PACT](#)

and unique contribution as a multi-stakeholder partnership focussing on equitable patient access, using the 5 'A's as a framework, whilst collaborating closely with other initiatives to bring patient access to the wider discourse. Its vision, mission and overarching objectives (see Annex 1), as described in the statutes should remain the same.

A more accurate assessment of PACT's resourcing requirements can then be made, with the premise that in the future, the organisation should be lean and effective, a convener, catalyst and facilitator, rather than taking on board directly very major projects and conferences itself.

Patient Access Solutions, and Scaling these

We need to move beyond ensuring patient access is on the political agenda, to also looking at selected evidence-based, workable solutions that can be showcased, replicated and scaled throughout Europe. This does not mean doing this ourselves but rather, acting as a catalyst to find mechanisms and partners to identify such solutions, assess them critically, and for PACT to provide an environment, through workshops, whereby they can be promoted, understood and the drivers for transformational change can be agreed, in a multi-stakeholder, multi-disciplinary way. It is likely that many of these solutions will be digital innovations linked to access, and rely on responsible health data sharing. This is not an arena into which PACT will venture per se, as it is a vast and complex terrain, however, PACT partners will pinpoint exceptional flagship digital health initiatives with proof of concept, which merit assessment. More specifically, it has been suggested, in the immediate term, PACT should also address shortages as this is a prominent topic of increasing concern across communities and governments alike.

We need to unleash appropriate resources to achieve this, and expand PACT's partner base according to criteria agreed by the steering group, to ensure we have sufficient expertise and commitment, and also find a way of thoughtful collaboration with wider 'health' networks at global, European, and national level.

Geographical Remit and Emphasis

We need to think again about our geographic focus. The impetus for the creation of PACT came from Central and Eastern Europe, acknowledging the lack of access, even to the most basic of care, in some parts of the region. Given the limited resources, and the desire for PACT to optimise its impact, we could justify, in the future, a particular emphasis on CEE, whilst not excluding other EU member states, joining forces with other relevant networks in the region that have grown from grass roots level.

We need also to be attentive to global movements that have an impact, directly or indirectly on patients' access to quality healthcare, focused on evidence-based policy making, and that can amplify our work. The Well Being Economy Alliance and the Global Alliance on Patient Access are two such examples. A dialogue with both in the near future will identify specific synergies and encourage mutual support.

Facilitating shared learning

A major focus of the new Commission will be cancer, through the 'Beating Cancer' Plan and the Cancer research mission. This provides an opportunity for PACT to accompany positive advances in cancer, *through the lens of access*, and with relevant stakeholder groups, through workshops, look at how these could be adapted in other disease areas. It will also help to create

a balance between political focus on cancer and other disease communities, encouraging similar comprehensive, mission driven and outcome-oriented approaches.

Becoming a more demanding voice

Since the beginning of PACT, one of its most successful activities has been the MEP Interest Group on Patient Access. Assessing carefully the other Platforms and interest groups proposed within the new European Parliament that address health, there remains a clear need for an interest group focused specifically on access. More emphasis in this mandate should be placed on equitable access to primary prevention, as well as treatment and care options, and also the coordination work needed to maximise the ‘access’ dimension of disease specific/ topic specific interest groups. Further efforts are needed to ensure that the composition of the Interest Group includes influential members from other sectors beyond health, recognising that access conundrums are often multi-faceted. Our work in the European Parliament should, in future, become far less ‘informational’ and much more ‘campaigning’ and catalytic with a very clear message that equity of access is a human right, and with concrete end political goals in mind.

Important political reference points for PACT’s work going forward

As we look at the wider environment, there are several political reference points that underpin both our raison d’être and our future direction, extracts of which are listed below. This is not exhaustive but point to the need for PACT’s work, the importance of a multi-stakeholder approach and collaboration with wider initiatives on the ‘access’ component.

- Sustainable Development Goal 3 of the 2030 Sustainable Development Goals
Specific target on Universal Health Coverage
Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.
- Mission Letter of Stella Kyriakides, Commissioner for Health
- *Europeans expect the peace of mind that comes with access to healthcare, safe food to eat and protection against epidemics and diseases... Europe has some of the world’s highest standards on animal and plant health, as well as the most affordable, accessible and high-quality health systems to deliver on these expectations. At the same time, we are becoming an older society and need more complex and expensive treatments. This brings into sharp focus the need to support the health sector and the professionals working within it, to invest in new technologies, to promote healthy lifestyles and to cooperate better within the EU.*
- *To ensure Europe has the supply of affordable medicines to meet its needs.*
- 2019 report on the State of Health in the European Union

- *Gaps in health care accessibility are still very much a reality in the EU. Both the clinical needs and socioeconomic characteristics of patients need to be accounted for when measuring access to health care and its many barriers.*

- EU Health Coalition Recommendations from the November 2018 Summit

- *Establish a Forum for Better Access to Health Innovation*

A multi-stakeholder forum on better access to health innovation should be created to discuss barriers and solutions to further innovation. ... facilitated by the European Commission involving all stakeholders – including national and regional authorities, patients and civil society, healthcare professionals and industry – which would discuss drivers and barriers to access innovation, including economic, budgetary, organisational and regulatory. In addition to innovative technologies, the Forum should also discuss the introduction of related healthcare services and care pathways, and how to address barriers and inefficiencies created by fragmented organisational and financial models. The work should be based on solid data from horizon scanning and monitoring of access to innovation

- *Facilitate multi-stakeholder partnerships with regions and cities*

Fostering an environment of cooperation with local and regional stakeholders would help to further tackle the health inequalities that persist in Europe. When defining health policies at EU level, there should be more coherence at the European, national and regional levels. More cooperation at national and regional levels regarding treatment and prevention is needed. In order to achieve this, organisational and financial coherence is paramount. Regions and cities are close to the citizens and therefore best placed to understand their health needs, challenges and the potential workable solutions. Examples such as the European Innovation Partnership on Active and Healthy Ageing (EIP AHA) showed the added value of mobilising a variety of stakeholders across the value chain, under the European Commission guidance, focusing on a set of shared priorities. The principles and the process of this experience should be replicated also in the future and used as a tool to reinforce the dialogue at local, regional and EU levels. With 6,000 health-related projects financed through the European Structural and Investment Funds (ESIF), cohesion policy showed its crucial contribution in supporting social and economic convergence around Europe. Moreover, the smart specialisation strategies represent an important instrument for coordinating different policies and funds at local level and should be further leveraged. For this reason, the cohesion policy should be allocated sufficient resources in the future programming period, as it represents a long-term investment policy for all regions and cities in Europe.

- *Ensure better access for patients to cross-border healthcare*
- PACT Conference on the Sustainable Development Goals

The need for a stronger role for civil society in shaping health policy development and more ‘health enabling environments and economies’; ‘people-powered healthcare’

should be put in place; this may be possible if connections with regions and civil society multi-stakeholder platforms are made

The desirability of the EU-level setting minimum standards in health care, as a guide for Member States given that health is a basic human right which should be at the core of EU policymaking.

The need to identify the priorities of other policy areas as the health aspects of these priorities can provide useful entry points for cooperation making health a priority for other than health sectors and policy makers to advance their own goals

PACT as a patient- led initiative

PACT was established by NPO and the European Patients' Forum as a patient-led multi-stakeholder partnership. 'Patients in the driving seat' is a fundamental principle and we have been successful in PACT and EPF in aligning our approach, reinforcing mutual work on patient access, without duplication. A good example is PACT's support of the EPF campaign on UHC in 2017. It is important that this dynamic continues and there remains unequivocal support from the EPF President, board and secretariat for PACT and its work. This can be achieved in practical terms by ensuring optimal communication between the policy coordinators of the respective organisations.

A refreshed 'Partnership Strategy'

Looking back, a perceived added value of being part of the PACT was the 'light touch' towards partnership, which resulted sometimes in lack of commitment and ambiguity. With this new overall strategic approach, we need to revisit our existing partners, listen to them carefully regarding their aspirations, reaffirm their commitment to contribute, and formalise this so that there is more clarity of expectations on both sides.

We need to establish certainty and confidence with partners that have dipped in and out over the years, by making sure that the value proposition and the rules of engagement are absolutely clear.

We need a mapping exercise regarding further gaps in our Partnership at European level, and reinforced representation from the HCP community, research community and the Institutions.

With regard to more geographic emphasis on CEE countries, we need to establish a strategic relationship with the CEE Health Policy Network and CEE4Health. Both platforms house the expertise to support our work on identifying workable solutions to patient access across the region, As mentioned above, we also need to explore opportunities to advance our agenda on equitable access at global and European level, but our work in the CEE environment should be very focused on the gaps that exist, and crucially the solutions to address these.

We need to hold strategic discussions with other multi-stakeholder initiatives on health (the EU Health Coalition, All Policies for A Healthy Europe, the EU4Health Coalition) to work out a modus operandi, and offer to support the 'access' related aspects of their work. The Health Coalition's two recommendations outlined above are a case in point.

Our Governance structure should be expanded to reflect a widening and more active partnership with each 'sector' being appropriately represented.

Our relationship with the EU Institutions

We have a strong relationship with the European Parliament, which we are in the process of reigniting. The Commission has been supportive over the years, albeit sporadically, approaching PACT when there was a need. A high-level meeting with the Commission will be vital in the near future, to discuss the new strategic approach of PACT, and to explore how this might be resourced. Given that we are looking at 'pearls of excellence', across Europe - viable solutions to fundamental access problems - we need to look thoroughly the EISF funding base and opportunities for assessment and scale up work in relevant projects.

We need to work more closely and systematically with each EU Presidency on equity of access and ensure that it is integral to their health agendas. Our work with the Finnish Presidency on the access dimension of the Economy of Well Being was an excellent example. We should look at the opportunity of a small-scale initiative under the current Croatian EU Presidency as an illustration of our intent here. Intelligence work is crucial in the context of the German EU Presidency, as this is likely to be fertile group for deeper discussion on access in all its guises.

Funding Approach

At its inaugural meeting, PACT made a commitment to only accept funding from trade associations for its operational arm, whilst partners could fundraise from individual companies for specific activities. This has been effective to date but as the expectations for PACT evolve, and as the credibility and trust in the organisation is enhanced, we need an agreement at the next Partners ' Assembly that we can be more flexible with regard to our funding base, also accepting a limited level of funding from individual companies for our operations as well as our projects, in accordance with a very strict framework on transparency, and governance. It could be made clear that this is only until we have been successful in obtaining a reasonable level of support from public sources. Under no circumstances will PACT cooperate with the tobacco industry, or work with organisation or networks which do.

A priority is to obtain funding from the Commission, through collaborating with relevant networks, and/or becoming a partner in relevant EU projects. EPF could potentially help to facilitate this, given their track record on involvement in EU projects, signposting relevant projects in which PACT's modest involvement would bring added value.

Summary

In summary, PACT's strategic direction over the next 5 years should cover two key pillars:

More assertive, goal oriented Institutional Relationships

- Ensuring that the Interest Group moves towards being **a real campaign engine and change agent** for equitable access to quality care as a fundamental human right with meaningful impact through its work. It involves MEPs from other committees and is

seen as a “facilitator” for other interest groups on health, specifically on ‘equitable access’ to maximise effectiveness.

- **Repositioning PACT within the new Commission** as a trusted and effective multi-stakeholder partner and a particular source of expertise on access in CEE (a known lacuna in the Commission). A mechanism is needed for on-going dialogue and proper resourcing through public funds in the medium-term.
- Early interaction with each EU Council Presidency, to look at the ‘**equity of access’ angle of the Presidency** and to define pro-actively PACT’s role (which may be small scale or large scale) to ensure this is central to health discussions.

Moving to solutions mode – unpacking what works, why and how we can replicate and scale, and deepening cooperation with wider health initiatives.

- There has been much work undertaken on measuring the gaps and inequities in patient access across Europe. We now need to move to identifying with partners and projects, **selected evidence-based solutions to patient access that can be replicated and scaled**, initiating this work with partners in CEE, and promoting these solutions within the wider Partnership, sister initiatives and the EU Institutions. PACT does not have the resources to do this in a comprehensive way, but can illustrate how **collaboration can lead to transformation and improved access for patients**. Such solutions can come from across the prevention, treatment and care continuum and can be explored in dedicated workshops. This can then be fed into the policy – making environment, creating a virtuous cycle of improvement.
- Similarly, PACT can help to share some of the outcomes of the ‘**Beating Cancer Programme**’ that focus on equitable access and explore with its partners how these could **be replicated in other disease areas** and similar outcome-oriented missions could be created.
- There are several wider multi-stakeholder collaborations on health, described earlier in this document. PACT will reach out to these to **agree its role in helping to drive the ‘access’ dimension of the work, reinforcing a culture of cooperation and maximum impact**, and avoiding duplication and fragmentation.

ANNEX 1

Vision

The Patient Access Partnership enables different health stakeholders to join forces to develop, drive and propose to the European Commission and the European Member States sustainable solutions to ensure equitable patients' access to quality healthcare in the EU. Stakeholders will actively participate in delivering these solutions.

Mission:

The activities of the PATIENT ACCESS PARTNERSHIP are patient-focused. Information and knowledge transfer are a key requirement to identify gaps in and measure access to quality healthcare between and within member states. The PARTNERSHIP will develop a tool to monitor and measure equity of access in member states on an on-going basis. Through holistic collaboration with relevant EU-led or national initiatives, the PARTNERSHIP will provide a much-needed space for creativity, coherence and collaboration and propose sustainable solutions.

Objectives:

Access to healthcare remains unequal in Europe. By creating a structured partnership approach with a broad range of national and European actors ranging from patient groups, healthcare management and delivery, medical and health technology, national and European institutions, individual experts in healthcare and others, the PATIENT ACCESS PARTNERSHIP will identify key hurdles in access to healthcare for patients in a holistic way. While the approach is to look at healthcare systems as a whole, the activities of the PARTNERSHIP will be guided by a patient focus, from the assessment of gaps in access to quality healthcare among Member States, to the collaboration with relevant EU-led or national initiatives and the development of solutions.

The objectives of the PATIENT ACCESS PARTNERSHIP are:

- To facilitate the dialogue between European and national health stakeholders according to the mission;
- To identify key hurdles in access to healthcare for patients in a holistic way;
- To assess gaps in access to quality healthcare within EU member states;
- To collaborate with relevant EU-led or national initiatives;
- To develop innovative and sustainable solutions.