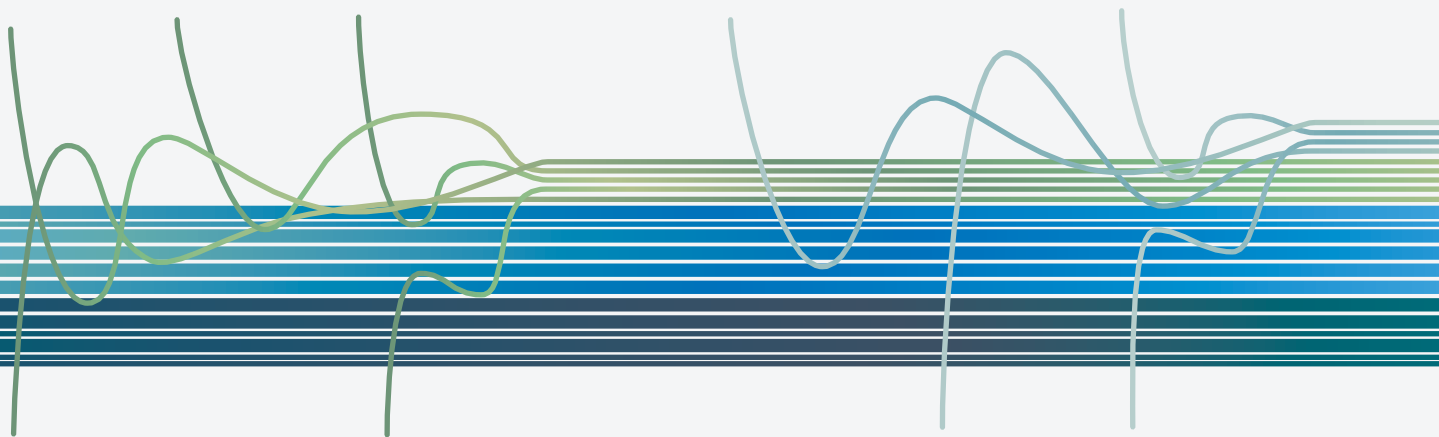


PARTNERS

Progress Report YEAR 1 (2018)



The rising tide lifts all boats

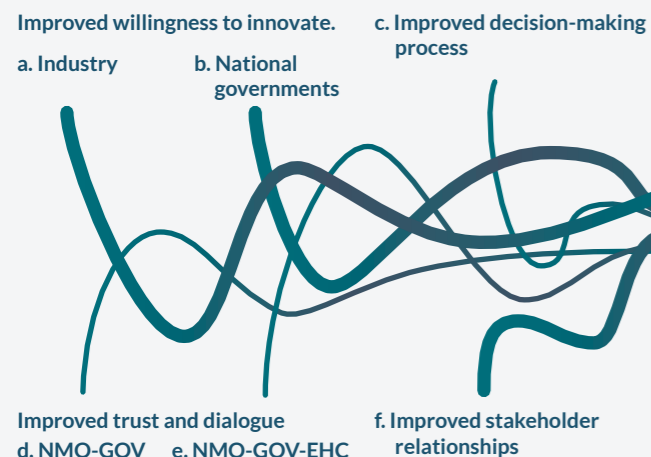
The implementation of PARTNERS is divided into four stages across three phases of countries. As expected, we see the most progress in phase 1 countries, which are most advanced, and some in phase 2, where dialogue has begun. Work is in embryonic stages in Phase 3 countries.

PHASE 1 COUNTRIES

Macedonia, Romania, Serbia, Ukraine, Kyrgyz Republic

STAGE 1

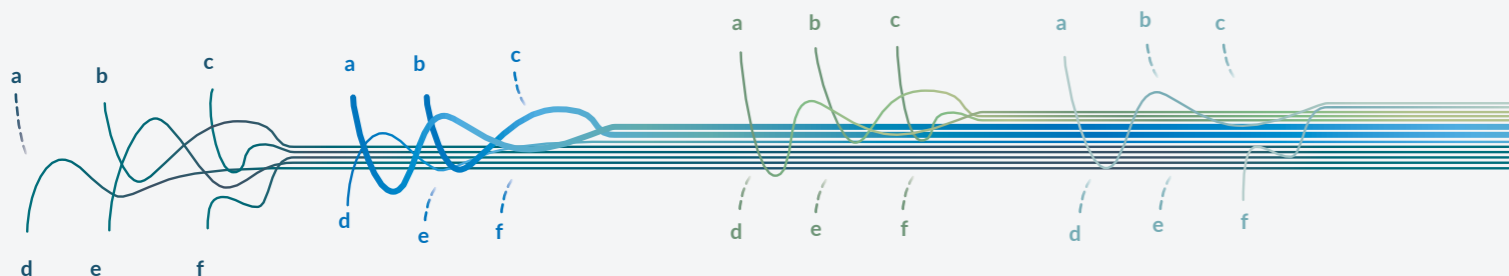
Dialogue and trust building



PHASE 2 COUNTRIES

Albania, Azerbaijan, Bulgaria, Latvia

See Phase 1 above for the definition of the categories.



PHASE 3 COUNTRIES

Armenia, Belarus, Bosnia and Herzegovina, Estonia, Turkey

No progress to report yet.

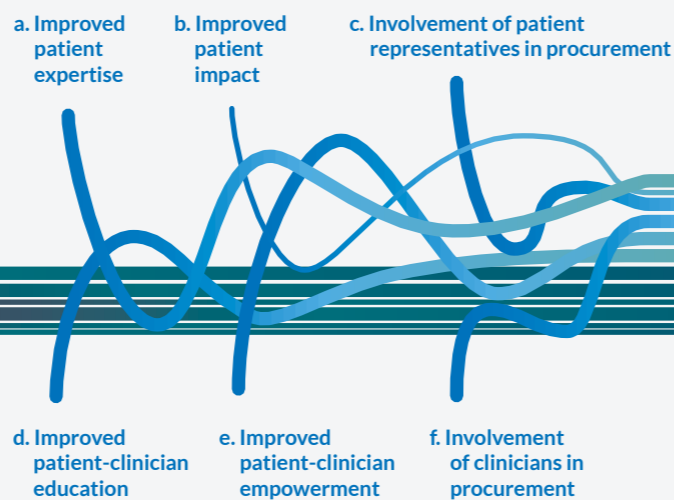
LEGEND

In the river metaphor below, each indicator is represented by an affluent that reaches the main river to 'raise the tide' towards treatment levels recommended by the Council of Europe.

- Moving forward reliably
- Moving forward slowly
- In development

STAGE 2

Vision, education and empowerment



About PARTNERS

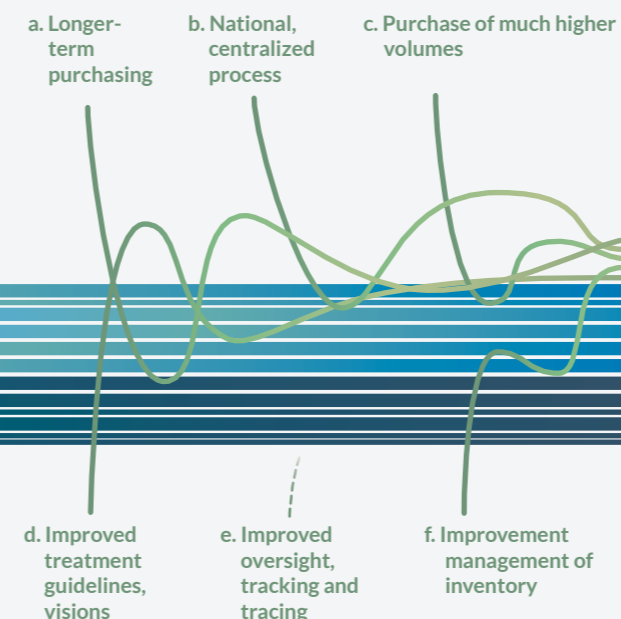
PARTNERS is a bold and visionary programme. Its ambition is to incentivize, enable and sustain better national haemophilia decision-making systems by changing relationship systems and creating new channels towards joint decision-making.

About this report

In this one-year report, we capture the progress-made to-date with a data visualization tool of moving water to

STAGE 3

Health care and procurement systems

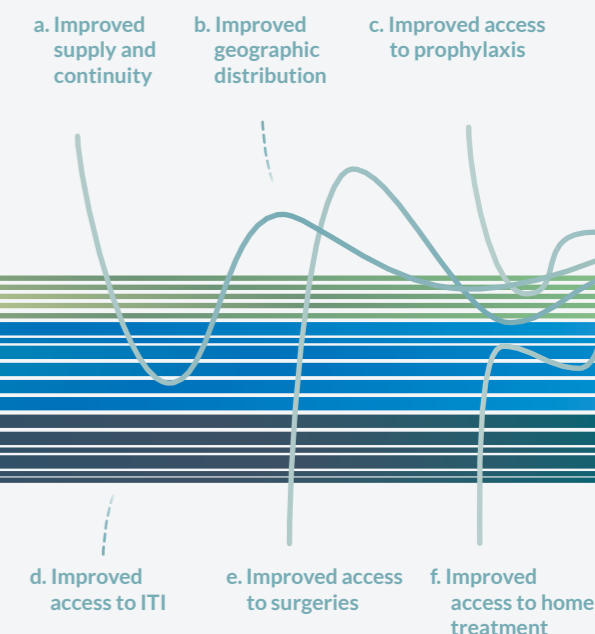


Achievements to-date

One year in, the greatest success of PARTNERS is the mind-shift that it created. This allowed us to establish dialogue and build relationships (and some trust) in all phase 1 and 2 countries. We report a behavioural shift in most phase 1 and 2 countries, with high willingness to innovate and new relationship channels being opened or existing ones improved. From these have flowed: patient representatives previously trained by the EHC on economics, tenders and procurement,

STAGE 4

Availability and patient access



illustrate the gulf that needs to be filled between where PARTNERS countries begin, where they need to go^{1,2}, and how PARTNERS is working to get them there.

To put this into context, the national allotted amount for a child (<18) with haemophilia in a PARTNERS phase 1 country for one year is equivalent to what an infant (0-4) in a Western European countries might use in one month.

The visualized water stream(s) also indicates the staged, staggered yet flexible approach in which PARTNERS aims to do this, and illustrates our efforts to build new channels, or redirect existing ones, to raise the national tide that will lift all patients towards European standards of treatment and care.

now putting these skills to use; patient representatives having their first conversations with governments over involvement in national decision-making; patient representatives contributing for the first time to considerations of other criteria in national tenders, not just price; and clinicians being trained on planning for better treatment. We have also seen down-stream effects, triggering the possibility of reviewing national treatment guidelines, establishing national registries, building 'track and trace systems' and ensuring better continuity of supply. There is much work ahead, but with the pull of a strong, foundational current, we head into year two confident that:

The patient whom we met this year in a PARTNERS phase 2 country, who went to the hospital with a headache and slipped into a coma because the country was not currently in a procurement cycle, might be the last patient we lose in Europe to red tape and bad planning.

1 Giangrande PLF, Peyvandi F, O'Mahony B, et al. Kreuth IV: European consensus proposals for treatment of haemophilia with coagulation factor concentrates. *Haemophilia*. 2017;23(3):370-375. doi:10.1111/hae.13211.

2 Giangrande P, Seitz R, Behr-Gross ME, et al. Kreuth III: European consensus proposals for treatment of haemophilia with coagulation factor concentrates. *Haemophilia*. 2014;20(3):322-325. doi:10.1111/hae.12440.

The **European Haemophilia Consortium** (EHC) is an international non-profit organisation that represents 46 national patients' organisations of people with rare bleeding disorders from 27 Member States of the European Union (EU) and most Member States of the Council of Europe.

As part of its support for National Member Organisations (NMOs) to improve the quality of life of people living with rare bleeding disorders and to ensure adequate supply of and access to safe treatments, the EHC has developed the Procurement of Affordable Replacement Therapies - Network of European Relevant Stakeholders (PARTNERS) programme.

A real partnership initiative, this programme is a new and innovative approach to the sustainable procurement of treatment products for haemophilia A and haemophilia B in select countries meeting EHC specified criteria and located both inside and outside of the European Union.

In several countries with developed healthcare systems but highly limited budgets, the volume of treatment necessary to effectively treat haemophilia is not available. This results in lack of treatment or under-treatment for people with haemophilia, which has a significant impact on the health and quality of life of people with haemophilia living in those countries. The main objectives of the PARTNERS programme are to work with national healthcare systems to:

- Enable countries to provide adequate levels of treatment products, to improve access to treatment for people with haemophilia.
- Involve clinicians and patient representatives in the procurement process to seek to improve treatment sustainability for healthcare systems.

The PARTNERS programme is an effort by multiple stakeholders to sustainably increase access to haemophilia therapies. The main eligibility criteria for the programme are countries where:

- Current use of FVIII replacement is <4 IU per capita and/or current use of FIX replacement <0.5 per capita;
- Prophylactic treatment is not available to all children with severe haemophilia;
- National government, healthcare providers and National Member Organisations (NMOs) and manufacturers agree to participate in the PARTNERS programme;

- National authorities agree to:
 - Use national-level purchasing processes for treatment products;
 - Formally include clinicians and EHC NMO representatives on a long-term basis in the procurement system;
 - Award contracts to the winning bid(s) of at least a three-year duration;
 - Increase purchase of treatment products without decreasing the national haemophilia budget and agree in principle to at least double the current national purchased amount of haemophilia therapies over the three year duration of contracts awarded or until the minimum standards set by the European Directorate for the Quality of Medicines and Healthcare (EDQM) at any given time is met.

The development of PARTNERS also requires the commitment of companies manufacturing haemophilia products. To make the programme successful, by achieving a sustainable level of access to products for patients in eligible countries, companies committing to involvement in the programme must express a willingness to participate in the national purchasing processes of the eligible and participating countries and agree to provide those therapies in the participating countries at a price below a maximum price.

This programme is overseen by a multi-stakeholder advisory group composed of the EHC Steering Committee, EHC scientific and medical advisory group, external legal, regulatory and policy advisers, and representatives of participating companies manufacturing haemophilia products.

Industry partners on this programme include:

