Introduction to Public-Private Partnerships and other Collaborative Approaches Delivering Information to Patients on Diseases and Treatment Options in Europe

The purpose of this document is to provide an idea of different models of existing collaborations and partnerships in Europe delivering information to patients on medical conditions and treatment options, considering the possible partners, structures, process, outcomes and funding. Its main objective is to clarify the existing possibilities in setting up initiatives with parties from different sectors and how each partner can contribute to the realisation of the projects.

The report does not intend to evaluate the success of any initiative or to assess the information provided to the public. All the projects mentioned in this document were submitted by members of the Pharmaceutical Forum while conducting an analysis of practical implementation of partnerships/collaboration for information package at national level. An overview table mapping out the main characteristics (structure and membership; roles and responsibilities of the partners; budget and sources of financing; outcome; impact) of partnerships/collaborations submitted by the Members of the Pharmaceutical Forum is annexed to this report.

For the purpose of this report, the concepts of partnerships and collaborations are understood in the broadest sense. There is indeed not one single approach in building partnerships with the objective of developing and providing information on diseases and treatment options to citizens and patients. The pre-condition for including partnerships or collaborations in this report was the decision of different actors to gather expertise and resources in a single project aiming at informing patients. The experience has shown how diverse and complementary existing approaches can be. Considering the different possibilities from the structures and outcomes of the partnerships, a number of examples were selected in the overview table to illustrate the diversity. The initiatives listed should constitute experiences of interest when developing future cooperation between different partners.

Who are the partners?

There are many kinds of partnerships in the Member States. The general principle is that parties launch joint projects when there is interest in sharing experiences, resources and knowledge. The variety of approaches presented to the working group has shown that initiatives can involve multiple possibilities of public-private collaborations and public-public collaborations. Examples of private-private collaborations also exist in some Member States.

For the Medicine Information Project, a public-private partnership in the UK, NHS Direct online, is the provider of information on conditions and treatment options. In addition, there is the Medicine Guide, independently authored by health experts and subsidised by individual companies, which is directly interlinked with NHS Direct online. Interested parties such as industry, patient organisations, the UK Department of Health and healthcare professionals jointly supervise this initiative. The Medicine and Reason project in Austria is another example of a public-private partnership where the Minister of Health is not involved directly but where the association of Austrian social security institutions, an independent
administration, is working with the Medical Chamber, the Chamber of Pharmacists, the Chamber of Commerce and the Austrian pharmaceutical industry association.

Public-public partnerships also exist in Europe. For instance, individual Swedish county councils launched Health Care Direct, a website and phone advice service on health services disease information and treatments in Sweden. Actors representing different activities and different interests share expertises and resources for specific initiatives resulting in further information to patients on diseases, treatments and health topics.

How are partners involved in the projects?

The roles and responsibilities of the partners are very diverse. In some initiatives, partners are involved only as resource providers, i.e. providing funding or knowledge. Orphanet, for example, is a government service headed by INSERM, the French Institute for Health and Medical Research. For some of its ad hoc projects, such as the provision of information on orphan drugs and on clinical trials, the private sector is involved by providing financial support.

Partners might also contribute by providing initial information, to be used as a basis for the end product. This is the case, for example, with FASS.se, where the pharmaceutical industry provides information on pharmaceutical products – package leaflets, SPC, etc. to the national medical product register. In other projects, partners provide factual content on health/disease topics.

In other initiatives, parties are involved at a later stage in the production of information. In a number of cases, independent experts are in charge of the drafting of information and stakeholders, including patient organisations, healthcare professionals and sometimes industry, are involved through being consulted on the text. This is the case with "Informed Health Online" (Gesundheitsinformation.de) in Germany, for instance.

Finally, all partners can also be at the core of projects, being deeply involved throughout all stages of the development of the projects. This kind of involvement can be organised in different ways, e.g. within the board of trustees (Informed Health Online), or within a Steering Committee (Informatum in Denmark and Medicine and Reason).

What are the possible outcomes of partnerships?

Most of the initiatives on information to patients on diseases and treatment options that were mentioned to the Pharmaceutical Forum focus on electronic information. A number of websites created by partnerships which disseminate information on diseases and/or pharmaceutical treatments already exist in the UK, Germany, Sweden and Denmark. Other possible non-electronic outcomes of collaborations are flyers, drug guides, guidelines, fact sheets, newsletters and phone advice.
**What about validation?**

From these examples, it seems that a common trend exist regarding the validation process of information. In general, initiatives have clearly defined validation systems in place. As part of the process, there are usually two key safeguard mechanisms. Firstly, the draft material is presented to independent expert groups for a first review. Afterwards, as a final condition before publishing, the text is usually sent for validation by a review group, usually composed by stakeholders.

The liability of the sources of information is of major importance.

**How are the outcomes disseminated?**

It should be mentioned that initiatives resulting from collaborations between different parties are sometimes directly linked to or even integrated within public authorities’ websites. This is the case in the UK, with NHS Direct Online, and in Germany with the website of the German Institute for Quality and Efficiency in Healthcare. Other initiatives are separately promoted, such as FASS.se or Orphanet. Dissemination of the outcomes can also be carried out by specific members of the partnership. For Medicine and Reason, flyers are distributed by three of their funding members (the Main Association of Austrian Social Security Institutions via its Health Care Institutions, the Medical Chamber and the Chamber of Pharmacists) in healthcare settings, while, in parallel, all members have included the project on their websites.

**Impact**

Considering the different aims of the initiatives, the impacts of the collaborations mentioned to the Information to Patient Working Group are variable. Some initiatives can reach many citizens, illustrating the increasing need for information by patients. The Swedish FASS.se has 4 million visitors a month, of which 40% are patients or citizens. Orphanet has 20 000 daily users from 150 countries of which 33% are patients.

In addition to the extensive use of certain initiatives, the degree of satisfaction among users is also found to be high. 88% of users of the Medicines Information Project found the information to be of use, and 85% found the information to be trustworthy.

**Financing**

Funding of the projects can be either public or private. In the Medicine and Reason project, for example, the costs are shared equally by all four members (Austrian pharmaceutical industry association and the Chamber of Commerce are regarded as one member).

The financing systems of initiatives also vary. Indeed, the running of the initiatives can depend on annual contributions (Informed Health Online/Gesundheitsinformation.de), sponsorship of ad hoc projects (Orphanet), or even fees from pharmaceutical companies per product mentioned (FASS.se).

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1 The figures used in the report were provided by members of the Pharmaceutical Forum and are only indicative.
<table>
<thead>
<tr>
<th>Name – Member State</th>
<th>Structure and membership (link to legal basis and mandate if publicly available)</th>
<th>Role and responsibilities of the partners</th>
<th>Budget and sources of financing</th>
<th>Outcomes</th>
<th>Impact</th>
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| Medicines Information Project UK | Partnership including government, MHRA, NHS, pharmaceutical industry, patients, HC professionals [Details](#) on the website | Supervisory remit for the project, giving it overall direction and setting priorities | • Funding for development of the NHS Direct Online content about medical conditions and treatment options, provided by NHS Direct Online.  
• Funding for individual Medicine Guides provided by the pharmaceutical industry  
• The funding model is based on a fee per product and contribution to development and management costs based on companies’ turnover. | Medicine guide: guide about individual medicines with links to/from information about condition and treatment options published on NHS Direct Online  
• [website](#) | • Approaching 500 000 pages download per month  
• Survey about the information: 88% usefulness, 85% trust  
• Direct electronic interaction with NHS direct and the Health encyclopaedia |
| Medicine and Reason Austria | Partnership between main association of Austrian social security institutions, industry/Chamber of Commerce, medical chamber, pharmacist chamber. (Guideline for procedure, external quality assurance of abidance by this procedure) | • Members of the Steering Committee and of all other boards (expert group, implementation, evaluation)  
• After a first draft being developed by experts, stakeholders are consulted through roundtables | € 73 000 p.a. 25% paid by each partner | Flyers on disease and treatments for patients disseminated free of charge to Healthcare settings and in addition accessible on internet, and guidelines for general practitioners  
• 9 guidelines and flyers available (Jan. 2008)  
• [website](#) | • last printed edition: 260 000 flyers and 18 000 guidelines  
• support for general practitioners and patients  
• provision of state-of-the-art and evidence based therapies at an economically reasonable price  
• interdisciplinary approach |

1 This overview is not exhaustive or exclusive.
2 AIM and ESIP stresses that this overview should not aim to provide the basis for a recommendation for the establishment of collaborations or public private partnerships.
| **FASS.se**<br>Sweden | Pharmaceutical industry association involved in certain collaborations contributing to the website - Swedish Association of Local Authorities and Regions: Supply and development of information to the Swedish health care - Medical Products Agency, the Pharmaceutical Benefits Board and the National Corporation of Pharmacies : National Medical Products Register - Uppsala University: interactions and descriptive texts on certain topics - National Poisons Information Centre: overdose treatment - Swedish Environmental Research Institute: Validation of environmental classification - Stockholm county: Development of environmental classification | • Product information supplied by pharmaceutical companies.<br>• Other information by independent authors. | Individual pharmaceutical companies | **Website:**<br>• Patient FASS text on authorized medicines in Sweden<br>• 300 diseases and their treatments, 40 topics covering general aspects of use<br>• information about patient organisations<br>• R &D information for more than 60 diseases<br>• Access to ongoing and completed clinical trials<br>• Environmental classification<br>• Pregnancy and lactation classification<br>Accessibility for disabled people: Braille, text to voice, large font printouts and automatic translation of medical terms in SmPC and similar documents<br><br>**My Fass:** to store patients medications.<br><br>**Rapid alert function** available to disseminate information on product information updates.<br><br><br><br>**Medicines compendium:** Patient-FASS is biannual publication | **Website**<br>• 4 million visitors/mth with 40% visitors from general public/patients.<br>• Information distributed electronically to various information systems within the Swedish health care, pharmacies, etc.<br>• Off-line to PDA<br>• Access from mobile phones<br>• Information structured for electronic transmission and supports medical decision systems<br>• Main provider of information on medicines in Sweden<br>• Cross-reference to several public sites<br><br>**Patient-FASS:** 35 000 copies |

<p>| <strong>Sjukvårdsrådgivningen</strong>&lt;br&gt;(Health Care Direct)&lt;br&gt;Sweden | Partnership between county councils | Managed by a management board and editorial board. 85 employees working on the text. | Financed by the county councils with an annual budget of € 28 500 000 | <strong>Website</strong> with 1350 topics about diseases and drugs&lt;br&gt;<strong>Phone advice</strong> | <strong>Website</strong>&lt;br&gt;• 80 000 website visitors/mth&lt;br&gt;• 3.5 millions phone advices |</p>
<table>
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<tr>
<th>Medical Products Agency Sweden</th>
<th>Partnership with the health care, industry, and user organisations</th>
<th>Medical Products Agency: responsible for the production of information Other partners: advice and authorship</th>
<th>Website for the public on drugs and diseases</th>
<th>5200 website visitors / month</th>
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<tr>
<td>Partnership with the Swedish Medical Association</td>
<td>Medical Products Agency: production joint authorship</td>
<td>Included in the ordinary budget of MPA</td>
<td>Drug guide: 460-page book for the public on drugs and diseases</td>
<td>15 000 copies sold</td>
</tr>
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| Informed Health Online Gesundheitsinformation.de Germany | German Institute for Quality and Efficiency in Health Care cooperates with stakeholders in the final stage of the development of the information. Legal basis: Section 139a and 139b of Social Security Code Book V (SGB V) | Board of trustees (health professionals, patients, community and industry) Researchers in charge of the first drafts which scope and messages will be submitted for approval. Consultations are organised with Health Ministry and board of trustees; Test readers as a final stage | Non-government Foundation established by legislation, which is financed by statutory health insurance contributions and funding from the Ministry | Multiple international cooperation, including adoption of the patient information by NHS Direct and HAS |

| Infomatum Denmark | Partnership including government, pharmaceutical industry and organisations: Ministry of Health and Prevention, Industry Association for Generic Medicines, Medical Association, Association of the Pharmaceutical Industry, Medicines Agency, Pharmacy Association, Regions and Association of Parallel Importers Information on the website: http://www.infomatum.dk/ | Steering committee is responsible for 1. Impartial and knowledge based presentations on medicines and the most suitable use in patient treatment and 2. chooses members for the board of directors/executive committee Executive committee selects a steering group with representative of all the partners | Owned by DADL (Danish Medical Association) and DLI (Danish Medicinal Products Information) which have an annual turnover of DKK 45 million The publishing establishment is financed by the pharmaceutical firms which are members of the industrial organisations represented in the steering group | Guidelines for practitioners of medicines Objectives: - To improve the existing level of knowledge on medicines and strengthen the decision-making in connection with choice of treatment - To ensuring that patients get a treatment of high technical skill |

- Website
- Book
- Offline PDA
| Directorate of Health Iceland | Government agency headed by the Medical Director of Health. One function is to advise the Minister of Health and Government bodies, health professionals and the public on matters concerning health and health care services. Information about the structure on the [website](#). | • A clinical guidelines unit cooperates with other clinical guidelines providers, nationally and abroad, among them the Landspitali University Hospital. The unit makes use of foreign clinical guidelines and adapts them to Icelandic circumstances.  
• The DH unit of professionals chooses material for website information for the public on health and diseases. | Funded by the State  
Website:  
• Clinical guidelines for professionals (the most frequently visited pages on the DH website).  
• Information for the public on health and diseases with links to validated websites in English and in Icelandic. | Website:  
• 46 000 page impressions/month  
• 7000 visitors/month |
| Orphanet | • Consortium of 37 national partners  
• Independent national Orphanet teams with scientific advisory board and consortium agreement.  
• Central coordination by the French team.  
• Ad hoc cooperation with private and/or public organisations | • French team in charge of information on diseases written by experts and peer-reviewed; and of coordination with national teams to collect data on services at national level.  
• The scientific advisory boards advise the local teams and validates the national information.  
• Partners involvement depending on the project  
  - Financial support  
  - Data sharing from industry, clinicians and patients organisations. | • Core budget: Minister of Health of France, INSERM (National Institute of Health and Medical research) and European Commission  
Sponsor financing specific projects: Industry organisation, patient organisation and insurances.  
• Information mostly electronic:  
  1. Orpha.net: [Website](#)  
  - Database of information on rare diseases (5806 diseases) with direct link to a health encyclopaedia  
  - Database of information on orphan drugs (45 orphan drugs in Europe, 530 European designations, 591 clinical trials)  
  - Specific information per diseases with reference to: specialised clinics, diagnostics test, research activities including clinical trials and patients organisations  
  2. OrphaNews: Newsletter bi-monthly  
  • Languages: English, French, Spanish, German, Portuguese and Italian | • 20 000 daily users from 150 countries. Users: 33% patients and they entourage, 33% Doctors, 18% other health professionals  
• 96% satisfaction of Orphanet users |
List of websites:
3. Fass.se: http://www.fass.se
4. Sjukvårdsrådgivningen: http://www.sjukvardsradgivningen.se
5. Medical Products Agency (Läkemedelsverket): http://www.lakemedelsverket.se
6. Informed Health Online: http://www.informedhealthonline.com/Gesundheitsinformation.de
7. Infomatum: http://www.medicin.dk
8. Directorate of Health / Iceland: http://www.landlaeknir.is