Swiss PH Registry
Pulmonary arterial hypertension (PH) is continuous high blood pressure in the pulmonary artery.

PH is a severe disease and is often lethal by causing heart failure.

PH is an orphan disease and its diagnosis is very difficult.

80-100 cases were assumed to exist in Switzerland.

The main therapy has a potential to cause liver damage.

It is therefore crucial to measure liver enzyme levels regularly.
• The Swiss PH Registry has been designed in close collaboration with the SAPH, the Swiss group of top PH experts and the major Swiss universities

• The registry is sponsored by the manufacturer of the current “gold standard” PH therapy but open to all therapies

• User friendly internet based tool, no software installation needed

• Automatic email reminder function for liver enzyme test monitoring. Physicians are reminded repeatedly until the new liver enzyme test result is entered in the database.
Case Study
Internet based tool
### Site Statistics

Date: 09.09.2003 13:44  
User: Dr. Hanna Test, Basel, Test Country  
Country: Test Country

**Number of registered patients**

<table>
<thead>
<tr>
<th>City</th>
<th>User</th>
<th>Number of patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Basel</td>
<td>Dr. Hanna Test</td>
<td>12</td>
</tr>
<tr>
<td>Total centers in Test Country</td>
<td>26</td>
<td></td>
</tr>
<tr>
<td>Average per center in Test Country</td>
<td>6.5</td>
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</tr>
</tbody>
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• Four times more patients registered in database than initially expected to exist in Switzerland
• Centres participating doubled since PH registry exists
• Sponsor and experts gained surprising information about anamnesis, diagnosis, disease progression and therapy
• Gained cross centre knowledge improved diagnosis and therapy for patients
• Sponsor gained huge amount of credibility in the community of PH experts