Prioritization survey with members
Online Survey: IPPOSI priorities for 2017-2018

• Open from Dec. 15, 2016 – Jan 20, 2017

• Total Responses: 71

• 88% identified as IPPOSI Members

<table>
<thead>
<tr>
<th>Answer choices</th>
<th>Responses (%)</th>
<th>Responses (Number)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient or Patient Organisation</td>
<td>30%</td>
<td>22</td>
</tr>
<tr>
<td>Researcher or Medical Professional</td>
<td>26.75%</td>
<td>19</td>
</tr>
<tr>
<td>Company</td>
<td>25.35%</td>
<td>18</td>
</tr>
<tr>
<td>Gov. Body or Funding agency</td>
<td>2.8%</td>
<td>2</td>
</tr>
<tr>
<td>Representative Body</td>
<td>4.2%</td>
<td>3</td>
</tr>
<tr>
<td>Other</td>
<td>9.8%</td>
<td>7</td>
</tr>
</tbody>
</table>
59 different organisations / members

Selection inserted into wordcloud:
Vision
Early, equitable access to Health Innovation for improved patient outcomes

Mission
We are the collective voice of Patients, Science and Industry in enabling meaningful involvement in, and improved access to, Health Innovation

Strategic Priorities
- Build IPPOSI brand and profile as a consensus-building group that influences access to Health Innovation
- Actively advocate through our patient-led perspective for improved and equitable patient access to Health Innovation
- Promote meaningful patient involvement in Health Research and Policy

Principles
Building consensus; Contributing constructively; Developing evidence-based positions; Providing call-to-actions; Empowering patients
Q1: IPPOSI has agreed three strategic priorities for the period up to the end of 2020. Which priority would you prefer IPPOSI to focus on for 2017-2018?

Answered: 69   Skipped: 2

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Priority A: Build IPPOSI brand and profile as a consensus-building group that influences access to Health Innovation</td>
<td>10.14% 7</td>
</tr>
<tr>
<td>Priority B: Actively advocate through our patient-led perspective for improved and equitable patient access to Health Innovation</td>
<td>53.62% 37</td>
</tr>
<tr>
<td>Priority C: Promote meaningful patient involvement in Health Research and Policy</td>
<td>39.13% 27</td>
</tr>
<tr>
<td>Other (please elaborate)</td>
<td>1.45% 1</td>
</tr>
</tbody>
</table>

Total Respondents: 69
Q2: From the list below, indicate your three preferred interest areas for IPPOSI to focus on in 2017-2018? (max of 3 selections)

<table>
<thead>
<tr>
<th>Answer Choices</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Research (no specific therapeutic area); Precision medicine; clinical trial data disclosure; clinical trial recruitment and retention; patient involvement; bioethics; patient-reported outcome measures; adaptive design; public information</td>
<td>35.21% 25</td>
</tr>
<tr>
<td>Patient Access to Health Innovation; Health Technology Assessment; real-world outcomes; value-based health care; health technology design &amp; development; pricing; reimbursement and access</td>
<td>66.56% 43</td>
</tr>
<tr>
<td>Data/Health: Patient Registries, Electronic Health Records, Information architecture/Infrastructure, Data standards and standardization, data quality, bioethics, data protection, privacy</td>
<td>66.34% 40</td>
</tr>
<tr>
<td>Patient involvement: Person-centered practices and engagement; patient advocacy and empowerment; guidelines, tools, culture change; metrics, coordination of healthcare, chronic disease management</td>
<td>69.01% 49</td>
</tr>
<tr>
<td>Rare Diseases: Genetic Services, Orphan Drugs and Technologies, Centres of Expertise, National Plans and Policy</td>
<td>32.33% 23</td>
</tr>
<tr>
<td>Disruptive Innovation: Innovative science and technology, connected health, innovative therapies such as stem cells, regenerative medicine, gene therapies, etc.</td>
<td>12.38% 9</td>
</tr>
<tr>
<td>Regulatory Aspects: Developments in regulatory science; biosimilars; compliance &amp; adherence; combination products; medical devices</td>
<td>1.41% 1</td>
</tr>
<tr>
<td>Safety and Pharmacovigilance: Safety/pharmacovigilance best practices; benefit-risk assessment; risk-based monitoring; biosimilars; post-market safety considerations</td>
<td>9.86% 7</td>
</tr>
<tr>
<td>Translational Research: Discovery, Preclinical, Clinical Development, toxicology testing; gene editing, biobanking</td>
<td>11.27% 8</td>
</tr>
</tbody>
</table>

Total Respondents: 71
If the topic(s) you are interested in are not listed, please describe them in the box below:

• Personalized Medicine
• Integrated care
• Measure and address inequalities in health service provision
• Campaign governments for more funding for basic medical research
• Support the wholistic patient journey
• Linking with Palliative care PPI opportunities
• Defining the meaning of IPPOSI membership (accountability, ethical)
• Legal Training for members