## Q1 Contact Information

## Answered: 16 Skipped: 0

| ANSWER CHOICES | RESPONSES |  |
| :--- | :--- | :--- |
| Name | $100.00 \%$ | 16 |
| Organization | $100.00 \%$ | 16 |
| Address | $0.00 \%$ | 0 |
| Address 2 | $0.00 \%$ | 0 |
| City/Town | $0.00 \%$ | 0 |
| State/Province | $0.00 \%$ | 0 |
| ZIP/Postal Code | $0.00 \%$ | 0 |
| Country | $0.00 \%$ | 0 |
| Email Address | $100.00 \%$ | 16 |
| Phone Number | $0.00 \%$ | 0 |

# Q2 Please rank the following topics 1-5 in terms of your level of interest in focusing on them as part of a potential patient registry working group (1 being of most interest and 5 being of least interest) 

Answered: 16 Skipped: 0


|  | 1 | 2 | 3 | 4 | 5 | TOTAL | SCORE |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
| Business Development (e.g. Menu of Services, Business | 43.75\% | 25.00\% | 18.75\% | 6.25\% | 6.25\% |  |  |
| Plan, Budget/Cost Recovery) | 7 | 4 | 3 | 1 | 1 | 16 | 3.94 |
| Recruitment/Retention (e.g. Patient | 18.75\% | 31.25\% | 6.25\% | 25.00\% | 18.75\% |  |  |
| Education/Engagement, Marketing Materials) | 3 | 5 | 1 | 4 | 3 | 16 | 3.06 |
| Operational Efficiencies (e.g. SOPs, Best Practices) | 12.50\% | 25.00\% | 43.75\% | 18.75\% | 0.00\% |  |  |
|  | 2 | 4 | 7 | 3 | 0 | 16 | 3.31 |
| Technology Evaluation (e.g. Scorecard, List of Vendors in the Market) | $\begin{array}{r} 18.75 \% \\ 3 \end{array}$ | $\begin{array}{r} 6.25 \% \\ 1 \end{array}$ | $\begin{array}{r} 18.75 \% \\ 3 \end{array}$ | $\begin{array}{r} 31.25 \% \\ 5 \end{array}$ | $\begin{array}{r} 25.00 \% \\ 4 \end{array}$ | 16 | 2.63 |
| Governance (e.g. Committee Structures) | 6.25\% | 12.50\% | 12.50\% | 18.75\% | 50.00\% |  |  |
|  | 1 | 2 | 2 | 3 | 8 | 16 | 2.06 |

# Q3 Are there any other broad topics not mentioned above that would be of more interest to focus on as part of this working group? 

Answered: 5 Skipped: 11

Q4 Would your organization be interested in participating in this Patient Registry Working Group?


| ANSWER CHOICES | RESPONSES |  |
| :--- | :--- | :---: |
| Yes | $87.50 \%$ | 14 |
| No | $0.00 \%$ | 0 |
| Possibly | $12.50 \%$ | 2 |
| TOTAL |  | 16 |

Q5 Are you aware of any other Patient Registry Working Groups being conducted by another alliance/society?


| ANSWER CHOICES | RESPONSES |  |
| :--- | :--- | :--- |
| Yes | $13.33 \%$ | 2 |
| No | $86.67 \%$ | 13 |
| TOTAL |  | 15 |

Q6 Please share any other thoughts that haven't been addressed in the previous survey questions that would be important to consider in development of a Patient Registry Working Group

