REGISTRIES

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Registries in healthcare - Definition

Organized system for the collection, storage, retrieval, analysis, and dissemination of basic (but uniform and standardized) informations about individuals, focused around a specific diagnosis/treatment, using observational study methods.

National Committee on Vital and Health statistics, 2013
Registries in healthcare

**Aims**
- Provide first-hand informations, both per patient and per group
- Track trends over time
- Constitute the basis for participating in clinical research (Anyway registry ≠ clinical trial)

*The ultimate goal is not only measurement, but rather improvement in quality of care and outcomes.*

**Characteristics**
- Broad inclusion criteria and few exclusion criteria (No limits of numerosity for joining; No mandated approaches)
- Standardized definitions for data entry
- Easy and no «time-consuming» data entry
- Quality of data monitoring
CQ 28: Are national and international registries needed for the expansion of LLR?

Registries for laparoscopic liver surgery should be implemented so that large numbers of cases can be recorded for research and data monitoring. This is of paramount importance in the absence of randomized control trials and high level of evidence. Centers performing LLR should be encouraged to contribute their data for all patients, which should be regularly audited. Unification and a limited number of registries is encouraged.
International Laparoscopic Liver Society (ILLS) main mission is to facilitate the diffusion and education of laparoscopic liver resection for meaningful improvements in patient care.

- organization of a biannual congress dedicated to laparoscopic liver resection
- coordination of international registries
- helping in the education of surgeons wishing to learn these techniques including
  - travel grants
- provide a website serving as a forum supporting collaboration between surgeons interested in the advancement of laparoscopic liver resection techniques
World map of national registries about LLS
肝臓内視鏡外科研究会 腹腔鏡下肝切除の前向き症例登録
〜登録症例数,登録施設数の月別推移〜

合計
- 登録症例 3642例
- 登録施設 278施設

2015年 2016年 2017年
1月 2月 3月 4月 5月 6月 7月 8月 9月 10月 11月 12月

Update I Go MILS Registry: 1678 prospectively included patients

November 2014 – 3 July 2017

54 Open Centers
45 Enrolling centers
Promotor: Ghent University Hospital
(EC approval: January, 2017)

Online recruitment open from February 8th, 2017

- Consecutive recording of laparoscopic liver procedures
- Board members representing university and non-university hospitals of both language communities (French & Dutch)

Contacts: HBSurgerystudy@uzgent.be

Courtesy by Roberto Troisi
INCLUSION
(UNTIL MAY 2017)

- 3 Centers actively recruiting
- 75 cases (February – May 2017)
- 4 centers ready for inclusion
- 5 more centers starting the EC procedures

Courtesy by Roberto Troisi
Committee & Endorsment

Registry Coordinator
M. Abu Hilal (Southampton, UK)

Registry Committee
M. Abu Hilal (Southampton, UK)
L. Aldrighetti (Milan, Italy)
G. Belli (Naples, Italy)
I. Dagher (Clamart, France)
B. Edwin (Oslo, Norway)
B. Gayet (Paris, France)
O. Scatton (Paris, France)
R. Troisi (Ghent, Belgium)
Spanish registry

- Inspired and conducted by Dr. Esteban Cugat
- Run from February 2000 to March 2008
- Recruited a total of 182 patients from 15 Spanish units.
- Not web-based, (Questionnaire)

- Gave origin to several oral communications and 2 scientific reports:

  **Resultados iniciales del Registro Nacional de Cirugía Hepática por Laparoscopia**
  

  Hospital Mutua de Terrassa, Terrassa, Barcelona, Spain. • Hospital Vall d’Hebron, Barcelona, Spain. • Clinica Universitaria de Navarra, Pamplona, Navarra, Spain. • Hospital de Santa Cruz i Sant Pau, Barcelona, Spain. • Hospital Carlos Haya, Malaga, Spain. • Compültor, Hospitalario La Mancha-Centro, Ciudad Real, Spain. • Hospital de Navarra, Pamplona, Navarra, Spain. • Hospital de Son Llàtzer, Palma de Mallorca, Illes Balears, Spain. • Hospital de Bellvitge, Universitat de Lleida, Barcelona, Spain. • Hospital Universitario de Canarias, Las Palmas de Gran Canaria, Spain.

  Cir Esp. 2005;78(3):152-60

  **Laparoscopic liver surgery: 8 years of multicenter Spanish register**

  Esteve Cugat · Noelia Pérez-Romero · Fernando Rotellar · Miguel A. Suárez · Mikel Gastaca · Vicente Artigas · Jorge-Juan Olsina · José Noguera · Sagrario Martínez · C. Moreno-Sanz · Joan Figueras · Javier Herrera · Hermógenes Díaz · Jordi Caballé · Fernando Pereira


  Feb 2000- April 2005
  74 patients from 10 centers

  Feb 2000- March 2008
  182 patients from 15 centers

  Courtesy by Fernando Rotellar
Stopped after 8 years

- Difficulty to create a web-based registry
- Technical and economic issues
**Why do we need registries in Laparoscopic Liver Surgery?**

1. Provide the «real» state of the art of LLS, and not the «ideal» one
2. Track trends over time
3. Implementation of LLS programs
   - Start up
   - Development
4. Research projects
   - Registry based
   - Network based
5. Quality measurement and control
• The focus of clinical registries is on capturing data that reflect “realworld” clinical practice in large, representative patient populations.

• Well-designed and well-executed clinical registries provide insights into patient characteristics, comorbid conditions, patterns of care, quality of care, safety, clinical outcomes, and comparative effectiveness.
9527 laparoscopic liver resections from 179 series

1131 laparoscopic liver resections

- Created and operated by the Agency for Healthcare Research and Quality (AHRQ)
- Largest publicly available all-payer inpatient care database in the United States
- Database contains discharge data representing an approximate 20% sample of the United States hospitals.
- NIS database provides more than 100 data variables from each hospital stay including primary and secondary diagnoses and procedures, admission and discharge types, patient demographic characteristics, insurance type, length of stay (LOS) and hospital characteristics.
Why do we need registries in Laparoscopic Liver Surgery?

Provide the «real» state of the art of LLS, and not the «ideal» one

Track trends over time

Implementation of LLS programs
- Start up
- Development

Research projects
- Registry based
- Network based

Quality measurement and control
49 responding societies; 37 out of 49 (75.5 %) provided data from their National Registries. Among them, 34 had recorded all the procedures performed in 2013 in their National Registries.
Update I Go MILS Registry: 1678 prospectively included patients
November 2014 – 3 July 2017
54 Open Centers
45 Enrolling centers

Trend of enrollments in 2015-2016

↑ centers
↑ cases
Why do we need registries in Laparoscopic Liver Surgery?

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## Centers with >60 MILS

<table>
<thead>
<tr>
<th></th>
<th>N centers</th>
<th>Years of MILS activity</th>
<th>Years of I Go MILS activity</th>
<th>N tot liver resections</th>
<th>N tot open resections</th>
<th>N tot MILS resections</th>
<th>Ratio MILS/tot</th>
<th>Ratio MILS/tot pre I Go MILS</th>
<th>Ratio MILS/tot post I Go MILS</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>13</td>
<td>median 12</td>
<td>median 2</td>
<td>19587</td>
<td>16766</td>
<td>2821</td>
<td>14.4</td>
<td>10.5</td>
<td>29.5</td>
</tr>
<tr>
<td></td>
<td></td>
<td>range</td>
<td>range</td>
<td>(5-22)</td>
<td>(368-2589)</td>
<td>(66-607)</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

- **Ratio MILS/tot**: 14.4, range (6.6 - 26.5)
- **Ratio MILS/tot pre I Go MILS**: 10.5, range (2 - 21)
- **Ratio MILS/tot post I Go MILS**: 29.5, range (9 - 62.3)

- **Centers with >60 MILS**: 14%
- **86%**

- **Implementation**
### Complexity of cases

<table>
<thead>
<tr>
<th></th>
<th>Pre I Go MILS</th>
<th></th>
<th>Post I Go MILS</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>%</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>Minor</td>
<td>1477</td>
<td>90,7</td>
<td>991</td>
<td>87,1</td>
</tr>
<tr>
<td>Major</td>
<td>152</td>
<td>9,3</td>
<td>150</td>
<td>13,2</td>
</tr>
</tbody>
</table>

#### Implementation

- **LPS segments**
  - Pre: 86%
  - Post: 69.6%

- **Non LPS segments**
  - Pre: 14.3%
  - Post: 30.4%

- **Minor**
  - Pre: 91%
  - Post: 13%

- **Major**
  - Pre: 9%
  - Post: 87%
### Morbidity

#### Pre I Go MILS

<table>
<thead>
<tr>
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<th>Whole series</th>
<th>Open series</th>
<th>MILS series</th>
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<tbody>
<tr>
<td>% complicates</td>
<td>26,1</td>
<td>27,4</td>
<td>14,3</td>
</tr>
<tr>
<td>% uncomplicated</td>
<td>73,9</td>
<td>72,6</td>
<td>85,7</td>
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</tbody>
</table>

#### Post I Go MILS

<table>
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<th>Open series</th>
<th>MILS series</th>
</tr>
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<tbody>
<tr>
<td>% complicates</td>
<td>25</td>
<td>27,6</td>
<td>17,4</td>
</tr>
<tr>
<td>% uncomplicated</td>
<td>75</td>
<td>72,4</td>
<td>82,6</td>
</tr>
</tbody>
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[Graph showing morbidity percentages for whole series, open series, and MILS series before and after implementation.]
### Why do we need registries in Laparoscopic Liver Surgery?

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<td>Quality measurement and control</td>
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Predictors of incidental gallbladder cancer in patients undergoing cholecystectomy for benign gallbladder disease: Results from a population-based gallstone surgery registry

Carolina Muszynska, MD,^a^ Linda Lundgren, MD,^b^ Gert Lindell, MD, PhD,^c^ Roland Andersson, MD, PhD,^d^ Johan Nilsson, MD, PhD,^e^ Per Sandstrom, MD, PhD,^f^ and Bodil Andersson, MD, PhD,^g^ Lund and Linköping, Sweden

Surgery, 2017

Risk of thrombosis and thromboembolic prophylaxis in obesity surgery: data analysis from the German Bariatric Surgery Registry

C. Stroh,^1,2^ N. Michel,^1^ D. Luderer,^1^ S. Wolff,^2,4^ V. Lange,^5^ F. Köckerling,^5^ C. Knoll,^6^ T. Manger,^1,2^ Obesity Surgery Working Group, Competence Network Obesity

DOI 10.1007/s11695-016-2182-4

Original Contributions

Has Metal-On-Metal Resurfacing Been a Cost-Effective Intervention for Health Care Providers?—A Registry Based Study

Ruth Pulikottil-Jacob,^1^ Martin Connock,^1^ Ngianga-Bakwin Kandala,^1,2^ Hema Mistry,^1^ Amy Grove,^1^ Karoline Freeman,^1^ Matthew Costa,^1^ Paul Sutcliffe,^1^ Aileen Clarke,^1^

PLOS One, 2016

Determination of the Oswestry Disability Index score equivalent to a “satisfactory symptom state” in patients undergoing surgery for degenerative disorders of the lumbar spine—a Spine Tango registry-based study

Miranda L. van Hooff, MSc,^a,b^ Anne F. Mannion, PhD,^c^ Lukas P. Staub, MD, PhD,^d^ Raymond W.J.G. Ostelo, PT, PhD,^e^ Jeremy C.T. Fairbank, MA, MD, FRCS

Spine Journal, 2016

Clinical Study
National trends with a laparoscopic liver resection: results from a population-based analysis

Jin He, Neda Amini, Gaya Spolverato, Kenzo Hirose, Martin Makary, Christopher L. Wolfgang, Matthew J. Weiss & Timothy M. Pawlik

Figure 2 Proportion of complications stratified by the different types of laparoscopic liver resection (LLR) before 2009 and after 2009 stratified by the type of database
Why do we need registries in Laparoscopic Liver Surgery?

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- Research projects
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  - Network based
- Quality measurement and control
Integrating Quality Into the Cycle of Therapeutic Development

Robert M. Califf, MD, FACC,* Eric D. Peterson, MD, MPH, FACC,* Raymond J. Gibbons, MD, FACC,† Arthur Garson, Jr, MD, MPH, FACC,‡ Ralph G. Brindis, MD, MPH, FACC,§ George A. Beller, MD, FACC,‖ Sidney C. Smith, Jr, MD, FACC¶

Durham, North Carolina; Rochester, Minnesota; Houston, Texas; San Francisco, California; Charlottesville, Virginia; and Chapel Hill, North Carolina

Figure 1. Model for the integration of quality into the therapeutic development cycle.
«Quality measurement and improvement have become important aspects of modern clinical practice. Advances in health information technology have ushered in new tools, such as clinical registries, which simultaneously improve the quality of scientific research and clinical care while assessing eligible professionals in meeting federally mandated reporting requirements»

Curr Opin Urol, 2017

“Outcomes measurement and monitoring, if associated with auditing, feedback and public disclosure of data, lead to an improvement of the quality of care”

J Thorac Oncol, 2013
Unplanned Reoperation After Craniotomy for Tumor: A National Surgical Quality Improvement Program Analysis

Using an International Clinical Registry of Regional Anesthesia to Identify Targets for Quality Improvement

Profiling Individual Surgeon Performance Using Information from a High-Quality Clinical Registry: Opportunities and Limitations
Conclusions – The 5 W in LLS Registries

| ✅ *What:* | Prospective collection of basic (but uniform and standardized) information |
| ✅ *Who* | All centers performing LLS, without restrictions of numerosity |
| ✅ *Where* | Both on a national and international basis |
| ✅ *Why* | To provide the «real» state of the art of LLS, track trends over time, contribute to implementation of LLS programs, develop research programs and improve quality of care, define standards of care |
| ✅ *When* | ASAP |