

Developing and Building a Medical Registry

Building a Registry

Specifying and building a Registry is a lengthy process involving a sequence of well-defined steps:

1. **Define** the objectives
2. **Specify** the structure of the database – tables & data items
3. **Identify** the people responsible for data collection & entry
4. **Prototype** the data input screens and outputs
5. **Take advice** on which technologies to use
6. **Build** the database
7. **Build** the website
8. **Run** system acceptance tests
9. **Set up** users and administrators

Job done!

Building a Registry

1. Why have a Registry?

Define the reasons for wanting it as clearly and concisely as possible. Is it for:

- Research
- Publishing papers
- Analysing outcomes
- Monitoring selected conditions
- Tracking patients
- Submitting data
- Collaborating with other organisations

Building a Registry

2. What is it for?

Having decided why a Registry is needed, identify the outputs. Are they:

- Listings
- Summaries
- Monthly reporting
- Survival analyses
- Excel exports
- Research studies

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3. Who will be included?

Agree clear criteria for adding patients to a Registry.

Are they:

- Presenting with particular conditions
- Having selected diagnoses
- Undergoing selected procedures
- Requiring surveillance

Steps 1 -> 3 determine the framework of a Registry.

The next step is to agree the data to be collected

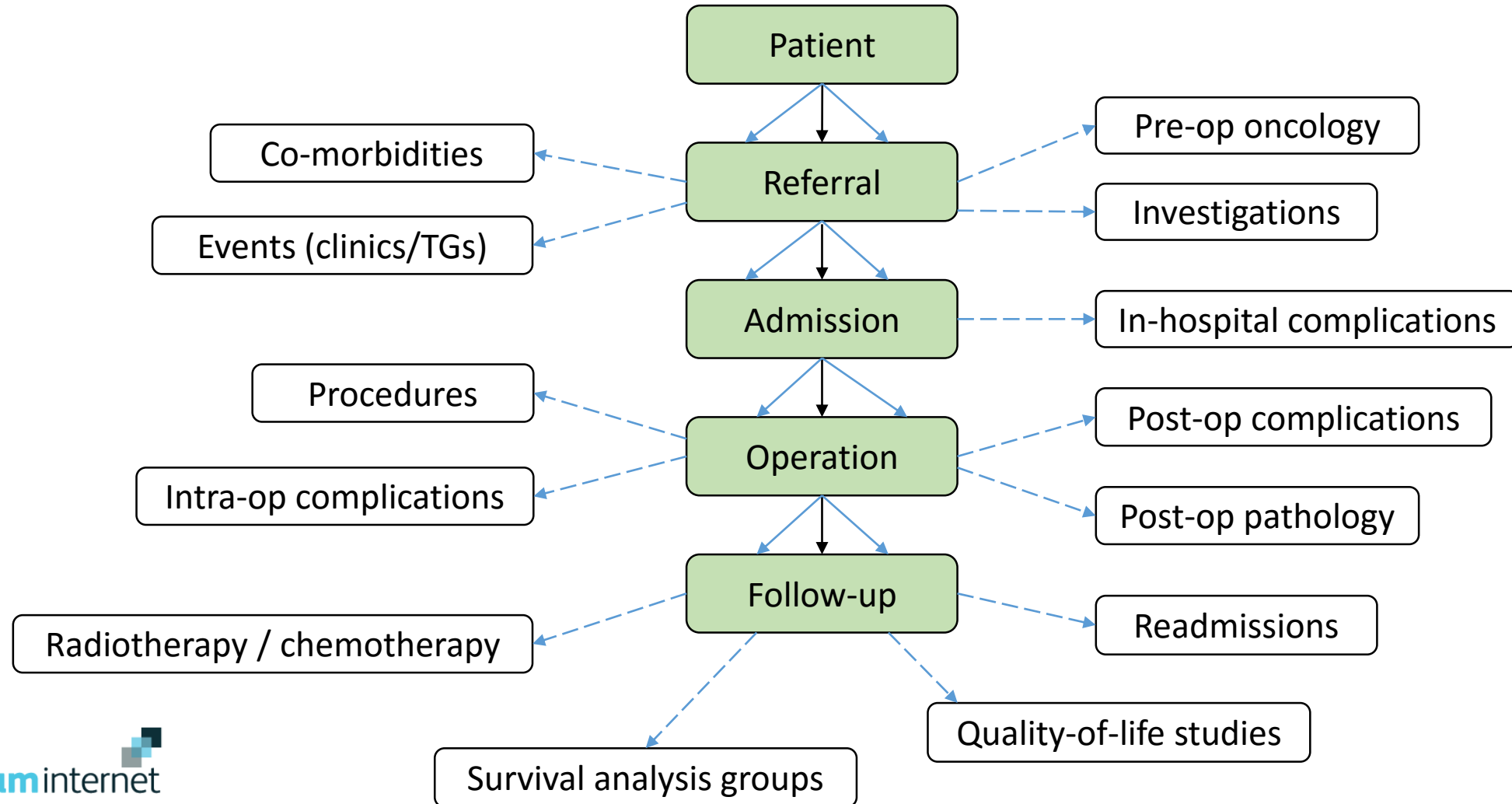
Building a Registry

Once the framework for a Registry has been agreed, the next step is to identify the tables in the database e.g.:

- Patient demographics
- Referrals (pre-operative)
- In-patient admissions
- Operations & post-operative
- Pathology
- Follow-ups

A core set of tables, the 'Patient Pathway', should be included to keep the database as flexible as possible for future development

The Patient Pathway



Building a Registry

Within each table in the database, define the data items to be collected. Specify whether:

- Key field linking to another table
- Mandatory / optional
- Encrypted / plain text
- Coded – for analysis
- Date
- Logical
- Numeric – integer / decimal
- Free text
- Image – jpg / png / gif

Prototyping a Website

Having specified the data items to be collected, the next step is to design the data entry screens and reports. There is prototyping software available that can be used to create the required look, feel and behaviour of a website without having to write any code.

Points to remember when designing web pages:

- Each data entry screen should contain similar items that can be completed by one person who is familiar with and understands what they are keying in
- Within a screen, arrange data items in small groups with meaningful titles
- Get early feedback from the people responsible for data entry. If they are involved with designing their screen(s), they will be better motivated to do their job to the best of their ability
- Ensure all data items in the database are included in at least one screen

Building a Registry

A detailed specification of the Registry has now been completed with:

- Data items grouped by category
- Prototyped data entry screens
- Report layouts / listings / graphics / images

The next step is to take professional advice on the development environment. Current industry standards for websites include:

- SQL server 2012 for the database
- Microsoft .NET with Entity Framework for the website

Specify if the Registry is to be available on iPads and mobile devices. .

Decide where the Registry is to be hosted and who will build, develop and support it **long-term**.

Summary

1. Agree *why* a Registry is needed
2. Identify *what* outputs are required
3. Select *who* will be included
4. Agree the main data categories to be collected
5. Specify the data items required within each category
6. Identify the people responsible for inputting the data
7. Prototype the data entry screens, reports, listings etc.
8. Get professional advice on the development environment
9. Commission a web development company to build the Registry

Remember

- Entering data is **time consuming**
Collect only the information required to achieve the objectives
Challenge every data item – why is it needed, how will it be used?
- **‘garbage in – garbage out’**
Ensure all data entered is of the highest quality
Do the people entering it understand what they are handling?
- Computer systems can always be modified
Start with a manageable system. Additional information, screens, listings, reports etc. can always be added later provided the database structure has integrity