



RD-CODE Workshop Country Presentation

Malta

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Malta: Sources

- > The Malta Congenital Anomalies Register (MCAR) - 70% of all its cases are rare: around 100-120 cases registered annually.
- > The Malta National Cancer Registry (MNCR) - 12% of incident cases matching rare disease diagnoses as registered in Orphanet: 240 new cases of rare cancers annually.
- > Treatment Abroad List of Patients (TA) - 60% out of all patients sent abroad who have documented rare disease (circa 350 per year.)

Content template

Country Info – Session 1, 2

RD-CODE

Malta specific

- Key Activities, Milestones
- Recent progress and Results
- Next steps and To do before the end of the project

Orphacode Training

- > RD-CODE 4 4.3 Orphacode Training report
- > The training programme was all set to happen on 3rd March. Covid19 has disrupted all work as all Public Health Physicians were enrolled in the emergency plan that is still in place
- > It is planned to have the training programme – virtually - in the coming months.

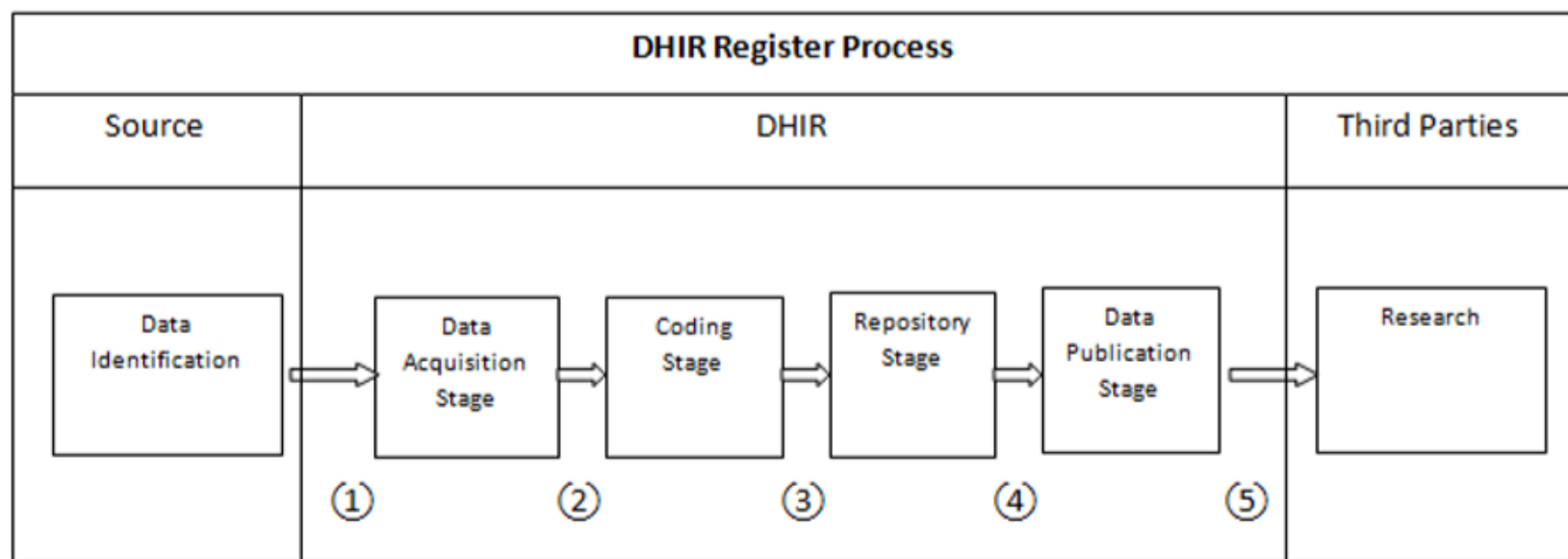
Delivery of technical solution

- > RD-CODE 4 MIs4.9
- > Delivery of a technical solution within the existing eHealth infrastructure (M15)
30/01/2020 30/03/2020 MFH

Developments

- > Connecting the various organisations and databases to our software required the production of APIs (application programming interfaces). - a first of its kind
- > POYC - pharmacy of your choice scheme – entitlement unit having access to updated schedules of treatment available to patients
- > Pathology laboratories which supply histology details etc, death register to update automatically on a weekly basis, congenital anomalies register) have been concluded.
- > Work flow logic has been collected from these sources and transposed electronically .

Workflow of data transfer



The common processes across all the DHIR Registry requirements are depicted by the figure above.

IT solution

- Regarding the software so far we have managed to complete the workflow of the rare disease processes from laborious tasks including compilation of excel sheets from various organisations and databases into an automated manner.
- Thus the framework of how the rare disease register will function is in place.

Technical solution

- > We are basing our final technical solution on the training session which aims to identify any gaps in our registry coverage and operation
- > The present digitization has replaced most of the manual work previously inherent in the system but we see this development as a further opportunity to further expand