

Developing an Irish National Diabetes Register

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AIM

- To recommend a methodology on how best to establish an accurate and complete register, in an efficient and effective manner, based on the practicalities of current Irish health systems.

Objectives

- To identify appropriate sources of data for the diabetes register
- To recommend a method of compiling and updating the diabetes register.
- To recommend a method of quality assuring the diabetes register.
- To make the above recommendations based on practical considerations of current Irish health service systems.
- To identify resources required to formulate a diabetes register.
- To make the above recommendations based on result of testing the accuracy and completeness of proposed data sources in the Mid West region.
- To make recommendations in compliance with data protection legislation.
- To recommend a minimum dataset needed to establish a diabetes register.

Methodology

➤ Six phases

Phase 1;

Identify data sources with individual demographic and diagnostic information.

- Medical card prescriptions (MCP).
- LTI.
- PAS (Diabetic Clinic).
- HIPE.
- Lab systems (LIS).

Phase 2

- Data extraction for matching, cleaning and de-duplication.
- Manual de-duplication, fuzzy de-duplication within each source using microsoft SQL Server Tool Kit.

Phase 3

➤ Data Hierarchy

➤ Criteria:

- Coverage
- Data Quality
- GP Data

➤ Decision:

- MCP
- LTI
- PAS
- HIPE
- LIS

Phases 4,5 and 6

Phase 4

- De-duplication across sources and creation of master file.

Phase 5

- Refinement of Master file, removal of deceased clients, outside area etc.

Phase 6

- Verification:
 - Surname verification
 - LIS verification
 - GP verification (pilot of 16 GPs)

Diabetics identified by each source

	MCP	LTI	PAS	HIPE	LIS	Total
Total number of individual records	5847	3461	2659	691	1749	14407
Proportion unique records	40.6%	24%	18.5%	4.8%	12.1%	100%
Number over 20 years	5765	3317	2479	687	1735	13983
IPH estimate						11270

Register has 19% more than IPH estimate

Summary of Findings from GP Verification Visits (7.8% sample: 1126/14407)

	MCP	LTI	PAS	HIPE	LIS	Not on Master file	Verification
Diabetic Client List	452	238	214	39	183		1126
Validated Diabetic	377 (83.4)	186 (78.2)	31 (14.5)	19 (48.8)	91 (49.7)		704 (62.5)
Not Diabetic per GP	40 (8.9)	22 (9.2)	91 (42.5)	7 (17.9)	67 (36.7)		227 (20.2)
Unknown	30 (6.6)	29 (12.2)	65 (30.4)	7 (17.9)	20 (10.9)		151 (13.4)
Deceased	1 (0.2)	0	25 (11.7)	5 (12.8)	2 (1.1)		33 (2.9)
Duplicates	4 (0.9)	1 (0.4)	2 (0.9)	1 (2.6)	3 (1.6)		11 (1.0)
New						28 (2.5)	

GP Verification estimated to full Register

	MCP	LTI	PAS	HIPE	LIS	Total
Total Unique Records (following refinement phase)	5847	3461	2659	691	1749	14407
% of Unique Records	40.6%	24%	18.5%	4.8%	12.1%	100%
% of Validated Diabetics (following sample GP verification exercise)	83.4%	78.2%	14.5%	48.8%	49.7%	62.5%
Estimated Validated Diabetics	4876	2706	386	337	869	9174
% of Estimated Validated Diabetics (as a % of 9174)	53.1%	29.5%	4.2%	3.7%	9.5%	100%

Completeness

- Total estimate = 9174 + 16% (unknown and new) = 10642.
- Reduce by 3% for over 20 year olds = 10323.
- IPH estimate = 11270.
- Difference = 947 i.e. 8.4%.
- If MCP and LTI sources only used register = 8452, i.e. 75% of IPH estimate.

Conclusions

- MCP and LTI are the most accurate sources for identified diabetics.
- PAS, HIPE and LIS represent poor value for effort required, due to data quality.
- Identification across all sources approaches IPH estimates.
- “undiagnosed” rate may be higher than 9.8% in ROI.
- Diabetics on diet only can only be identified by GPs.
- Irish Programme Studies and comparisons to full register needed.
- Barriers; lack of unique client ID and unique GP ID across sources.

Recommendations

- National Register to be formed using MCP and LTI data, directly from PCRS.
- GP verification annually.
- GP to register new diabetics.
- Self registration.
- DPC allowing use for retinopathy screening, consent at first appointment.
- NCSS will be managing retinopathy screening.

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