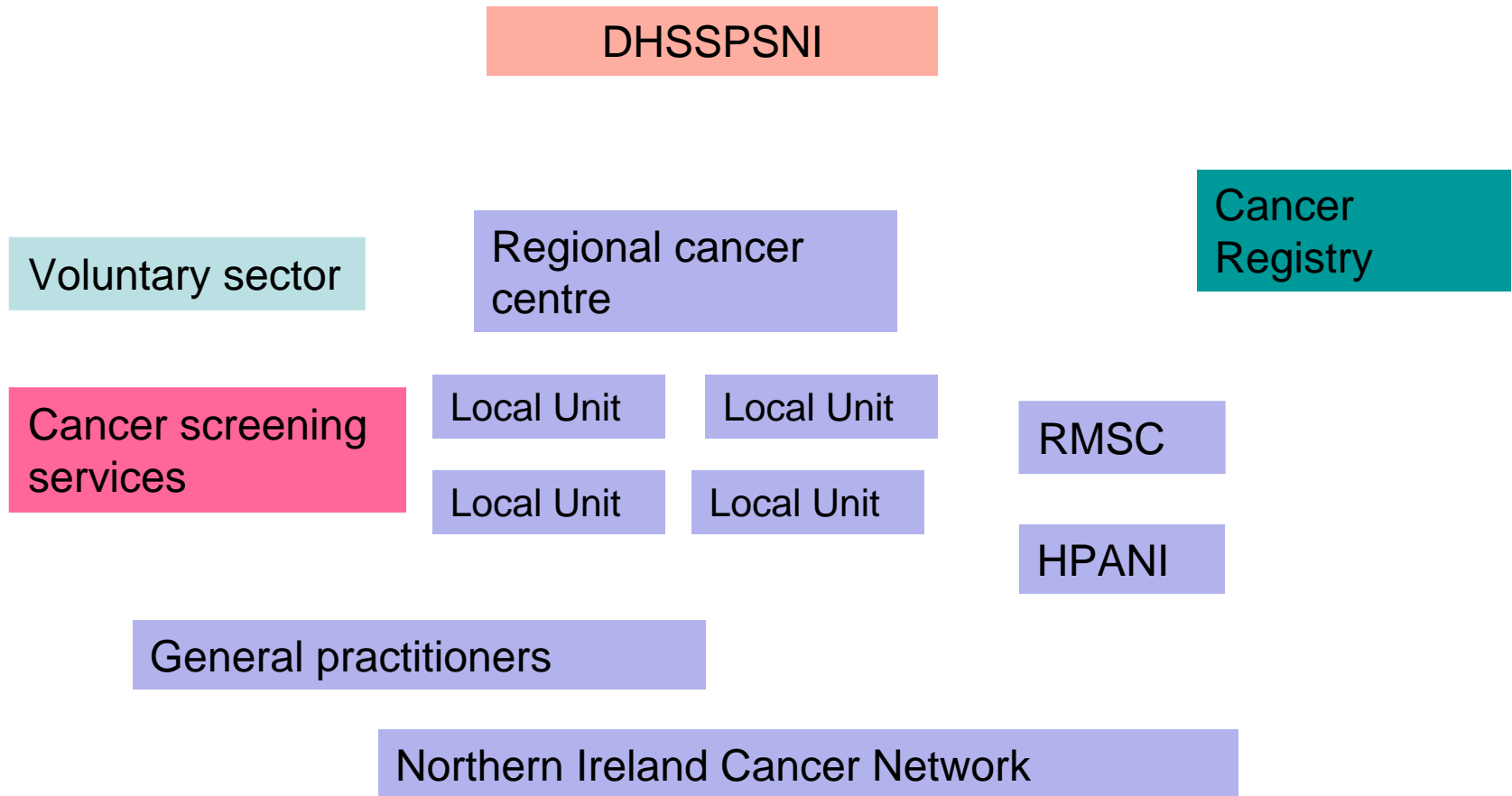


Availability of Information: Northern Ireland

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The “System” in Northern Ireland

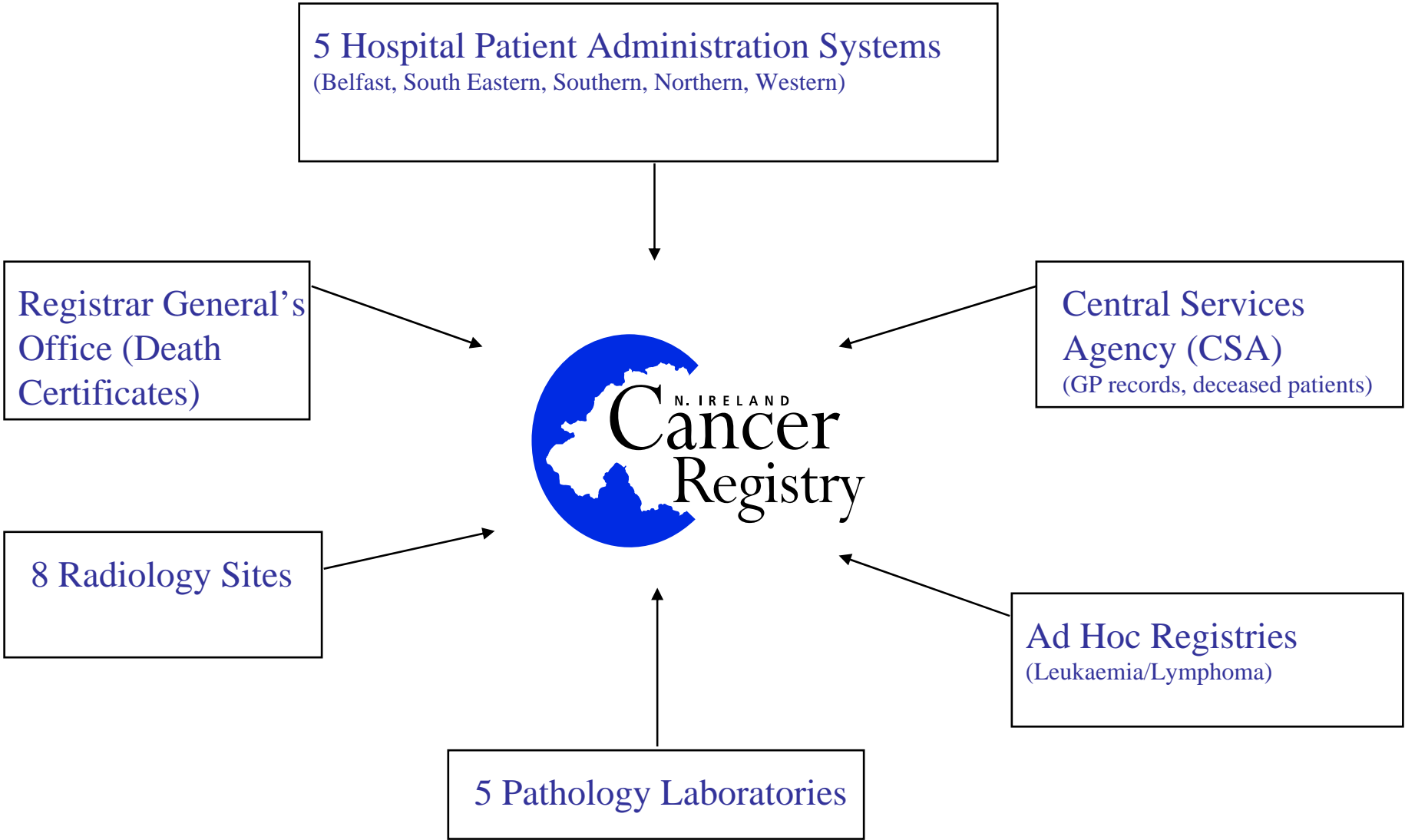


- Several actors/information points
- Recent review of public administration – individuals and agencies are changing
- Significant recent investment in cancer treatment



Data sources

- Northern Ireland Cancer Registry
- Northern Ireland Longitudinal Survey
- CSA and Other surveys



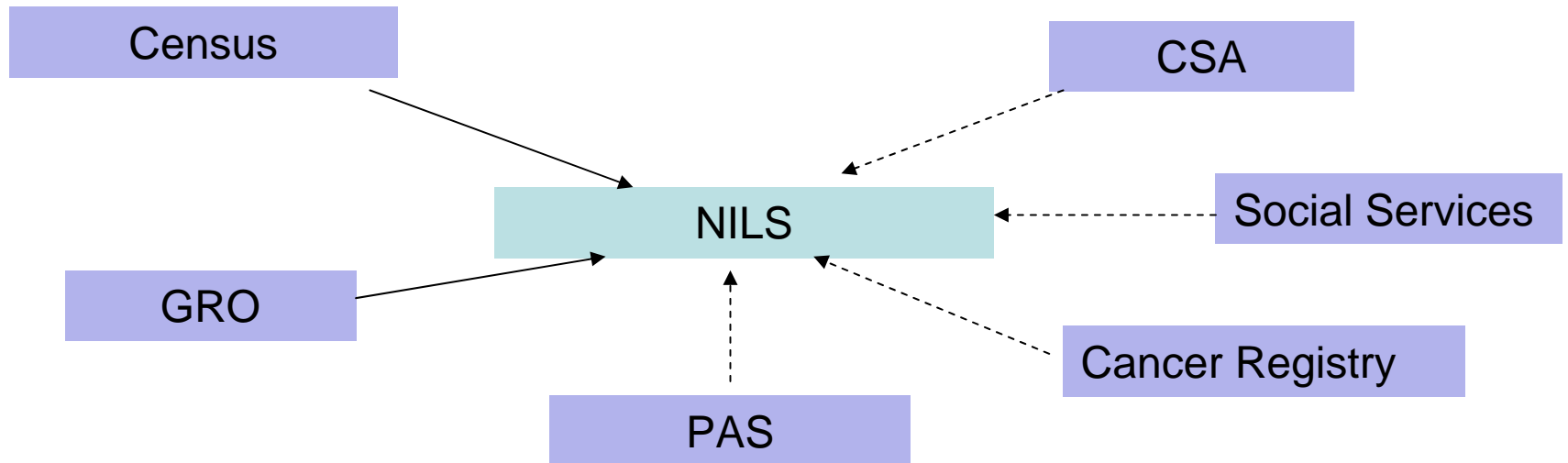
Current NICR Data Sources

www.qub.ac.uk/nicr

Northern Ireland Cancer Registry

- **Data**
 - Cancer type, staging, co-morbidities
 - Unique patient identifier with age, gender, postcode, hospital events, smoking history
- **Time period**
 - Diagnosis and death annual; other info based on periodic enriched surveys of patient notes 1996, 2001, 2006
- **Access**
 - By agreement with NICR with ethics committee approval
- **Coverage**
 - Population – 1.7 million
- **Continuing to evolve**
 - system to collect “live” decisions from multi-disciplinary team meetings

Northern Ireland Longitudinal Survey



Northern Ireland Longitudinal Survey

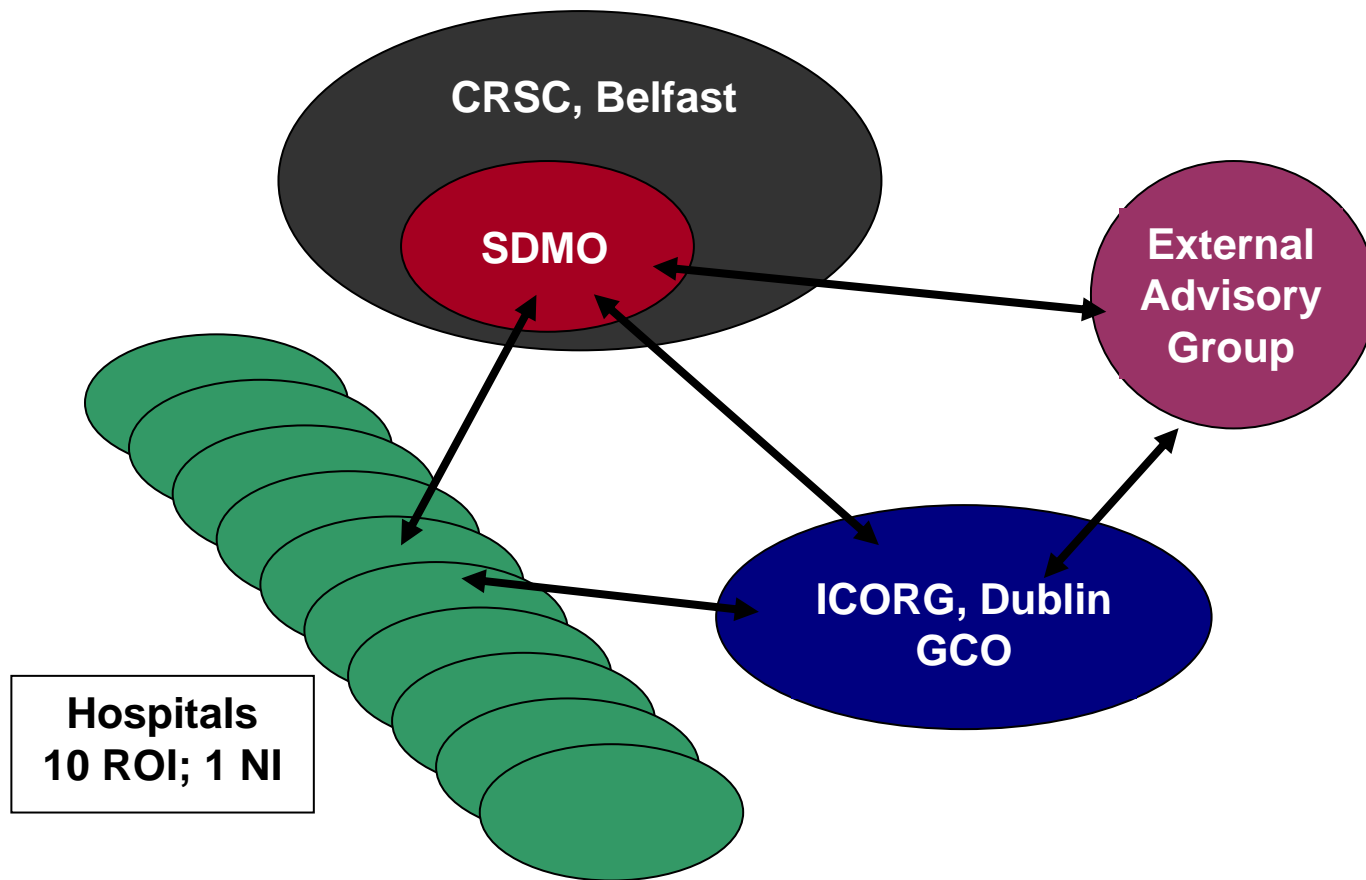
- Data
 - Census, births, deaths, marriages, soon CR, CSA, PAS, SSA
- Time period
 - Census 1991 (partial), 2001 census VE 1997-2007. Others hopefully in the next year current.
- Access
 - By agreement with contributing parties and ethics committee
- Coverage
 - Around 450,000 people are included in the Northern Ireland Longitudinal Study including other household members

Central Services Agency and Other Surveys

- CSA -
 - Family practitioner services – prescribing information potentially to an individual level; oral health; patient doctor contacts and tests.
- Northern Ireland Household Panel Survey
 - 2001 onwards, info on cancer limited
- HWS, CHS, OMS – don't deal with cancer
- NILT – very limited

Research Infrastructure

- **Clinical Research Support Centre (CRSC):** Regional resource funded by the R&D Office for the HPSS (Dec' 2002)
- **Core team:** Statistics, data management, IT, health economics, regulatory issues, trial monitoring, IP management
- **Statistics and Data Management Office (SDMO):** CRSC acts as the SDMO for the All-Ireland Cooperative Oncology Research Group (A-ICORG)



- Jointly funded by the R&D Office for the HPSS (NI) and the Health Research Board (HRB) in Republic of Ireland
- **Purpose:** to increase participation in high quality clinical trials in cancer

Other Investment in infrastructure by R&D Office for the HPSS (NI)

- Northern Ireland Clinical Research Network (NICRN) as part of the UKCRN
- Northern Ireland Cancer Clinical Trials Unit (NICCTU)
- Experimental Cancer Medicine Centre (R&D Office in partnership with Cancer Research UK - 17 centres in UK assigned ECMC status including Belfast)
- Ireland-Northern Ireland-NCI Cancer Consortium initiatives
 - Cancer Prevention Fellowship Programme; Clinical Trials Nursing Training
 - Summer Courses – principles and practice of cancer prevention and control; molecular prevention