Department of Health and Aged Care

Acute and Coordinated Care Branch

Consumer Consent in Electronic Health Data Exchange

Catalogue of Cases

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This document is a companion to the 'Background Paper' and 'Implementation Considerations', and is intended to be read in conjunction with them.

It is vital that the work undertaken in the project reflect the diversity of real-world circumstances, and lead to practicable processes and technologies. The purpose of this document is to identify and describe a sufficiently rich catalogue of cases, on which modelling, design and testing can be based.

Appendix 1 provides a catalogue of circumstances that may involve various forms of patient consent.

Appendix II identifies and describes three sets of cases:

- a core set, which provides the primary focus for the conception and development of prototypes;
- a mainstream set, which are to be borne in mind as the prototypes are conceived and developed; and
- a set of more difficult cases, which are to be borne in mind, but whose implications are to be considered at a later stage of the process.

APPENDIX 1: Catalogue of Circumstances

The following is a 'starter list' of circumstances that may involve various forms of patient consent. The intention is to provide an overview of the range of contexts involved. This list is complemented by Appendix 2, which presents some specific cases.

The list makes a working assumption that the term 'health care professional' is inclusive, and encompasses such people as doctors, physiotherapists, psychology professionals, pharmacists, community nurses, social workers, etc. It is independent of the basis of the employment relationship, and encompasses principals, employees, contractors, locums, etc. Occupations that are not 'health care professionals' include non-medical practice managers, nursing aides, secretarial staff, IT staff, transport services providers, cleaners, etc.

The organisational structure used in this Appendix is as follows:

- Clinical Issue
- Personal Data Collection Contexts
- Personal Data Disclosure Sources
  - Primary Care Contexts
    - Disclosures by Health Care Professionals
    - Disclosures by Other Staff
  - Hospital Contexts
  - Third Party Contexts
- Contexts Involving Proxies for the Patient
- Contexts Involving Special Sensitivities

1.1 Clinical Issues

- Chronic or Complex Conditions
- Acute Conditions:
  - encounter or event
  - episode

1.2 Personal Data Collection Sources

- From the Patient:
  - Interviews, Consultations
  - Forms
- From Clinical Work (this may be more recognised as Service Provision):
  - Notes, Observations
  - Diagnostic test reports/results
  - Discharge Summaries
  - Referral Letters
  - Care plans

- From Other Organisations:
  - Other Health Care Professionals
  - Diagnostic Services (e.g. Pathology)
  - Hospitals, out-patient clinics and emergency departments
  - Ambulance services
- Emergency Access to Personal Data (e.g. Wallet/Purse)
- Advice from relatives or associates of patient
- From Telephone Calls:
  - Notes
  - Calling Number Identification (CNI)
  - Telephone Conversation Recording

1.3 Personal Data Disclosure Contexts

1.3.1 Primary Care Contexts

(1) Disclosures by Health Care Professionals

- Health Care Operational Disclosures:
  - Referral Letters
  - Requests for Services (e.g. Pathology)
  - Discussions with Peers
  - Prescriptions
  - Team-Members
  - Care Plans and Instructions
- Notifications:
  - Family and Household Health Risk Notifications (incl. Child Abuse)
  - Public Health Risk Notifications under Statutory Authority
  - Public Health Risk Notifications under Professional Judgement
- Requests by Persons Closely Associated with the Person Concerned:
  - Guardians
  - Partners
  - Immediate Family
  - Household-Members
  - Adoptees
- Training of:
  - Health Care Professionals
  - Training of Health Care Students
  - Training of Administrative Staff
- Requests by Researchers:
  - Public-Funded Researchers
  - Academics
  - Private Sector Researchers
  - Official Registries, e.g. of Communicable Diseases, Cancer

- Requests by Complaints-Handling Bodies / Ombudsmen:
  - Health Care Complaints Bodies
  - Privacy Commissioners
  - Ombudsmen
  - Professional Registration Boards
  - Insurance Complaints Bodies
  - Professional Bodies
  - Industry Associations
  - MPs
- Requests by Claims Processors:
  - Medicare
  - Pharmaceutical Benefits Schemes
  - Insurance Companies
  - Investigators
- Requests by Quality Assurance and Accreditation organisations
- Requests by Law Enforcement Agencies (LEAs)
- Requests by Courts (including Coroners, Magistrates, Tribunals)
- Requests by Lawyers:
  - In Relation to Complaints or Suits Against the Person Concerned
  - In Relation to Complaints or Suits Against the Data-Holder
  - In Relation to Complaints or Suits Against Other Parties
  - In Relation to Probate
- Requests under FoI Legislation, and under Privacy Legislation
- Requests by Government Agencies:
  - Benefits Payment Agencies (e.g. Centrelink, DSS, DVA)
  - Community Services Agencies
  - Immigration
  - Foreign Affairs
  - Prisons/Corrective Services Agencies
  - Registries of Births and Deaths
  - Audit Offices
  - Guardianship Boards
- Requests by Other Organisations:
  - Corporations, e.g. in Relation to Selling
  - Not-For-Profit Groups, e.g. in Relation to Fundraising
  - The Media

(2) Disclosures by Other Staff

Generally, a significant sub-set of those for 1.2.1(a)

1.3.2 Hospital Contexts

Generally, a large sub-set of those for 1.2.1(a), plus additional ones, below:

- Discharge Summaries
- Referrals

1.3.3 Third-Party Contexts

- Medicare
- Pharmaceutical Benefits Scheme
- Insurance company

1.4 Contexts Involving Proxies for the Patient

- Persons in Loco Parentis
- Guardians
  - sole guardians
  - parents who are living together
  - joint guardianship, where the persons are not living together
- Persons holding Enduring Power-of-Attorney
- Next-of-Kin
- Executors

1.5 Contexts Involving Special Sensitivities

- STD Generally
- HIV/AIDS
- Abortion
- Gynaecological Conditions generally
- Circumstances that are or may be subject to misunderstanding or opprobrium in society generally, in some relevant culture, group or family, or in some context such as employment:
  - conditions, e.g. epilepsy, drug and alcohol dependency;
  - medications, e.g. prescriptions for contraceptives;
  - procedures, e.g. abortion, some kinds of cosmetic surgery
- Genetic Information, especially prediposition to diseases such as cystic fibrosis and breast cancer; and data that is capable of being used as a biometric
- Persons-At-Risk (e.g. Child-at-risk, Protected Witnesses, Battered Wives, Undercover Operatives)
- Celebrities and VIPs
- Identified Data that is presumed by the Patient to be Anonymous
- Health workers being treated by their employing organisation

APPENDIX 2: Catalogue of Cases

The following is a catalogue of specific circumstances that involve various forms of patient consent. The intention is to provide a degree of richness in the materials under discussion, in order to support greater depth of analysis.

Note that the term 'clinician' is used in this Appendix as an inclusive term referring to any health care professional.

This Catalogue is divided into three sections:

- **a core set of cases**, which provides the primary focus for the conception and development of prototypes;
- **a mainstream set of cases**, which are to be borne in mind as the prototypes are conceived and developed; and
- **a set of more difficult cases**, which are to be borne in mind, but whose implications are to be considered at a later stage of the process.

Each case is effectively a cluster of alternative scenarios. There are many dimensions across which the cases may vary.

A dimension of especial importance is **the degree of concern the patient has about the privacy of some or all of their health care data**. At least the following variants should be kept in mind in respect of each case:

- a patient who has great confidence in everyone in the health care industry, and is **trusting** of everyone with any and all of their personal data;
- a patient who is generally confident in and trusting of people in the health care sector, but for whom **one particular category of health care data** is very sensitive indeed, and they want it to be very carefully handled (e.g. an STD episode, a drug treatment episode, a condition that they perceive to be socially undesirable);
- a patient who is generally confident in and trusting of people in the health care sector, but who wants all data secure from **one particular person who works in a health care facility** (e.g. a wife, mother, cousin, business associate);
- a patient who is in the public eye, but who wants one category of their data to be very readily available to **emergency services** (e.g. a media magnate who suffers from heart disease);
- a patient who is seriously **untrusting** of all health care workers;
- a patient who is in the public eye, or otherwise at risk, and who wants their data stored under a **pseudonym**, as well as being subject to tighter-then-usual security arrangements (e.g. a VIP, celebrity, notoriety, victim of domestic violence, protected witness).

Appendix 2A: Core Cases

These provide the primary focus for the conception and development of prototypes.

Case A1 – A General Practitioner Refers a Patient to a Specialist

A general practitioner refers a particular patient to a particular specialist. This involves the provision of patient data to the specialist, and the presentation of the person at the specialist's surgey.

The specialist prepares a report. The report may be sent directly to the general practitioner, or provided to the patient to carry to the general practitioner. The specialist retains a copy of the report.

Case A2 – A Doctor Requests and Receives a Diagnostic Test

A doctor places a request for a diagnostic test in relation to a particular patient. This may involve provision of a sample of body fluid or tissue, or the presentation of the person at the diagnostic service's premises.

The diagnostic service prepares a report. The report may be sent directly to the doctor, or provided to the patient to carry to the doctor.

The diagnostic service:

- may or may not be aware of the patient's identity;
- may or may not retain a copy of the sample, of the report, and of materials generated during the testing process; and
- may or may not provide to some additional party a copy of the report, or other information arising from the process.

Appendix 2B: Mainstream Cases

These are to be borne in mind as the prototypes are conceived and developed.

Case B1 – Hospital Discharge Summary

A Registrar prepares a discharge summary for a patient who has spent a period in hospital. The hospital sends the document to the referring G.P., and to multiple specialist carers.

Case B2 – Prescription

A doctor writes a prescription for medication, and provides it to the patient.
A pharmacist fulfils a prescription written by a doctor, and brought to it by the patient.

Case B3 – Community Programme

An asthma sufferer participates in a programme involving multiple health care professionals at multiple locations within a region.

Case B4 – Planning of Community Care for a Patient on Discharge

A hospital team discusses a patient's needs preparatory to them being discharged. A member of the team discusses aspects of their needs with:

- the patient's carers;
- the family G.P.;
- a community health care professional;
- a community health care education organisation;
- a self-help organisation;
- a carer support organisation;
- a disabled transport organisation.

Case B5 – Community Care for a Terminally Ill Patient

A patient with termi cancer returns home with instructions to "have her G.P. monitor her serum Calcium". The patient doesn't have a regular G.P., and the community nurse who is dressing the patient's wounds calls a local G.P. to ask for help. The patient has no relatives in the vicinity.

Case B6 – Submission of Information to a Voluntary Register

A doctor submits information about a patient to a voluntary register of patients suffering from a particular condition.

Case B7 – Submission of Information to a Compuslory Register

In accordance with a legislative requirement, a doctor submits information about a patient to a register of patients suffering from a particular condition.

Case B8 – Clinical Trial

A person participates in a trial of a new medication or procedure.

Case B9 – Especially Sensitive Data

A woman is being treated for infertility. Unbeknown to her husband, she had a pregnancy termination many years earlier.

Case B10 – Explicit Denial of Consent

A patient is providing information to their G.P. In doing so, the patient expressly states that specific information is to be provided to no other person, under any circumstances.

~~G.P.G.P.~~

Appendix 2C: More Difficult Cases

Where possible, there are to be borne in mind during the development of the prototypes; but their implications are to be considered at a later stage of the process.

Case C1 – Patient is a Person-at-Risk

A patient is known by the health carer to be at risk of assault by some other person, should the patient's whereabouts become known to them.

Case C2 – Someone Else is a Person-at-Risk

Information about a patient is requested by a law enforcement or national security officer, without warrant, with the explanation that the patient:

- is known to have made credible threats against some other person or persons;
- is considered to be dangerous to some other person or persons; or
- is under suspicion of being a threat to some other person or persons.

Case C3 – Hospital Emergency, Leading to Coordinated Community Care

A person is admitted to hospital as an emergency case, and undergoes cardiac care. Information is sought by the treating clinicians from various local sources. Subsequently, the person is provided with coordinated community care.

Case C4 – Non-Emergency Case, Leading to Coordinated Community Care

A person is admitted to hospital, and undergoes cardiac care. Information is sought by the treating clinicians from various local sources. Subsequently, the person is provided with coordinated community care.

Case C5 – Comatose Patient

A hospital calls a G.P., advises that a person who is a patient of the G.P. is in a coma in the hospital, and requests patient data from the G.P.

Case C6 – The Locum

A patient indicates that they wish to be treated only by one member of a multi-clinician practice. The clinician is absent on holidays, and a locum is acting in their place. The following occur:

- the results of a diagnostic test ordered by the clinician arrive;
- a discharge summary arrives from the hospital;
- a specialist requests specified information from the patient's file; and
- a request for information, signed by the patient, arrives from an insurance company.

Case C7 – Parents and Guardians

A clinician treats three young people, one aged 17, one 14 and one 9; and a mentally handicapped person aged 25. One of the guardians of each of them comes to the clinic and:

- requests information about the patient; and
- asks the clinician to request data about the patient from another clinician.

Case C8 – Elderly Hip Replacement

Dr Watson has been Mrs Jones' preferred medical practitioner for a number of years. Mrs Jones, who is an elderly and independent woman, lives alone. Dr Watson has been monitoring Ms Jones' mobility for some time and has outlined and monitored a care plan to maximise her comfort and mobility. Dr Watson anticipates that surgery will be necessary and refers Mrs Jones to a consulting surgeon at the same time as monitoring her progress against the care plan until she can be admitted for surgery.

Ultimately, Mrs Jones is admitted to hospital for a hip replacement operation. With Mrs Jones' consent Dr Watson has included in his referral to the surgeon her care plan information.

Upon admission, from information contained in the care plan and with Mrs Jones' consent, the hospital notifies the following people: the HACC meals on wheels, transport and domestic assistance services. They will suspend their services to Mrs Jones until her discharge to home.

Following her operation, she is referred to a rehabilitation facility to improve her mobility before she returns home. To avoid any dusruption to her programme, the rehabilitation treatment team has been provided the care plan developed by Dr Watson, and the hospital discharge summary,. before she arrives at the rehabilitation facility.

Once Mrs Jones is sufficiently mobile to return home, relevant information, including recommendations relating to ongoing care, is sent by the rehabilitation centre, prior to her discharge, to Dr Watson, her local Aged Care Assessment Team, and home and community care services.

Dr Watson updates the care plan, schedules an appointment for Mrs Jones, and refers the revision to Mrs Jones' case managers at Aged Care and Community Care services.

G.P.G.P.G.P.Case C9 – Disclosure of Autopsy Reports for the Benefit of Relations

The brother of a G.P.'s patient suddenly collapses and dies at the dinner table, of no apparent cause. He is in his early 40s, and is thought to be in good health.

The G.P. seeks the preliminary autopsy information, in order to identify if there is any familial risk. (Autopsies usually take 12 months or so for the findings to be revealed). The next of kin (spouse) gives verbal agreement to the access, but nothing is documented in writing.

The G.M.O. concerned eventually provides verbal indications that the brother had died of severe coronary disease and a fatal MI. (He did not smoke or drink). This

information is invaluable in the risk assessment for the G.P.'s patient, who can now be advised to have further cardiovascular workup.

Case C9 – Pathology Laboratory Disclosure to New Treating Professional

G.P.s often have to chase up pathology reports for patients that had investigations or interventions completed during an A&E or outpatients episode. Patients clearly have a desire for the information to be transferred as they seek follow-up treatment with their usual G.P. or in some situations a new G.P.. In non-urgent cases, the G.P. and patient agree that the hospital episode information should be obtained for the G.P. to confirm and continue treatment. The G.P. writes to the hospital seeking a medical summary. More urgent cases are dealt with by telephone call by the G.P. and verbal summaries or facsimiled documents provided by Hospital Registrars.

Case C10 – Multiple Carers / Dispersed Records

A patient visits his local G.P. about his thick ankle. A pathology test is requested, and the ankle is x-rayed by a local radiologist. The G.P. is unable to make a conclusive diagnosis but commences an anti-inflammatory treatment regime.

The information is therefore held primarily by the G.P. as the primary health carer, and partially by the pharmacy, and the radiology and pathology service-providers. Some portions of medical information about the encounters, problem and treatment also reach the HIC.

The patient travels on business. As a result in part of work-related stress, the ankle becomes inflamed. The patient is too busy to visit a doctor during working hours, but limps into a locum service in the evening. The locum is unable to diagnose the problem. And because of the rush with which he left, the patient has left his drugs at home.

Reluctant to lose more work-time, the patient suggests to the locum that he access the results held by his primary carer, the pathology and radiology laboratories and the pharmacy, rather than waiting for nearby laboratories to open, process new samples, and report. He wonders whether the HIC records would be of assistance.

Unbeknown to the locum, and to the family G.P., the patient has visited another G.P. about a separate condition, which he would prefer not to disclose to the family G.P., or perhaps even to the locum. Tests ordered by the second G.P. were performed by the same diagnostic service-providers.

During the consultation with the locum, the patient mentions that he is sipping on a bottle of port a night but "forgot to tell" the family G.P..

The patient's clinical condition is heading towards diabetes, combined with gout, liver failure, renal collapse and work-related stress, and he is headed for intensive care intervention if the system can't help.

G.P.Case C11 – Incomplete Records

A hospital prepares a discharge summary for a patient, but has difficulty identifying who the primary carer is to send it to. Later, a G.P. calls the hospital, enquiring after the discharge summary.

Case C12 – Planning for Elderly Life

During an assessment of elderly life skill/status, a family G.P. asks a patient about their family-members' health status, and social status.

Case C13 – Health Research

A health researcher contacts a G.P., seeking information about a specific patient, in order to test variations from expected ranges.

Case C14 – Hospital Records Reconstruction

Hospital medical records or I.T. support staff contact a G.P., seeking information about a specific patient, in an endeavour to reconstruct patient records following the loss of a manilla folder, or database corruption.

Case C15 – Emergency Cardiac Episode

Mr Joe Alexander, a hypertensive male aged 45, experiences chest pains on a weekend and attends his local hospital's emergency department. On presenting, Joe advises the hospital that he wishes his G.P. to be kept informed of treatment.

The Triage Nurse notes the patient's advice of allergies and drug regime and determines that Triage Assessment is severe chest pain with priority 1, which is high.

The Emergency registrar collects a blood sample from Joe, orders an x-ray, connects a cardiac monitor, and re-affirms Joe's clinical history. He notes the drug history and Triage record, confirms that Dr Lewis is Joe's family G.P. and identifies that a Dr Wilson is Joe's current treating cardiologist. The Registrar also confirms that Joe's G.P. is to be advised that Joe is in hospital and asks about advising Dr Wilson. Joe decides not to advise Dr Wilson because of the Registrar's concern that it is Joe's drugs that are causing his pain.

Joe is admitted to the Intensive Care Unit. The head of ICU and the resident cardiologist assess Joe's condition and the new diagnostic results, emergency and ICU observations. They agree that a variation in drugs is required, combined with 24 hour monitoring until Joe's condition stabilises.

This appears to be a good decision, as Joe is scheduled to move from ICU to the cardiology ward and to be discharged after 60 hours subject to a new drug regime and a further 7 days under observation as an Outpatient equipped with a portable halter.

While being prepared for discharge Joe is asked if he would like his G.P. and cardiologist to be sent a copy of the discharge summary and drug history. Joe confirms that he would now like both to receive information relating to his discharge.

Fortunately for Joe, the hospital has adopted a range of Internet technologies to support its operations. The hospital has established two Web sites, one which describes its health services is via a commercial Internet service provider. The second creates an on-line Clinical Web Service with secure connections for authorised users, identical to that provided by commercial banking institutions. The hospital was also careful to separate its internal patient administration and clinical information systems from any risk of unauthorised on-line access.

Within this secure environment the hospital has provided a facility to act on Joe's first instruction that his G.P., and not his cardiologist, be advised that he is receiving emergency treatment in hospital.

The hospital's Clinical Web Server sends an e-mail to Joe's G.P., advising that one of his patients has been admitted, inviting the G.P. to visit the hospital's Clinical Web Server. Joe's G.P. is asked to click on a link included in the e-mail. By doing so, the G.P. is prompted for identification and password.

On successfully entering this information the G.P.'s screen is updated with a list of his patients who nominated him as their preferred general practitioner and who have had a recent admission.

A similar Web a service is available to Joe's cardiologist, in this case limited, by Joe's instructions, to discharge information only thereby keeping Joe's clinical team up-to-date following his discharge.