

STATES OF JERSEY



DRAFT REGISTER OF NAMES AND ADDRESSES (ACCESS FOR MEDICAL PURPOSES) (JERSEY) REGULATIONS 201-

**Lodged au Greffe on 14th May 2015
by the Chief Minister**

STATES GREFFE



Jersey

DRAFT REGISTER OF NAMES AND ADDRESSES (ACCESS FOR MEDICAL PURPOSES) (JERSEY) REGULATIONS 201-

REPORT

Introduction

The Register of Names and Addresses (Jersey) Law 2012 provided for the establishment of a register of names and addresses of individuals in Jersey for use by public authorities. These Regulations enable the register to be used by the Minister for Health and Social Services for medical purposes.

Background

The Register of Names and Addresses (Jersey) Law 2012 specified certain ‘registrable facts’ that would be maintained –

- name,
- address,
- date and place of birth,
- date of arrival in Jersey (if not Jersey-born),
- gender, and
- Social Security number.

The Law was designed to enable more and more public authorities to use the registrable facts over time. In this way, the register becomes more accurate and complete (the more Departments that use the register, the more sources it has to be updated from) and helps more Islanders interact with government (if they tell one department that uses the register that their information has changed, that also means other departments are aware of that change, i.e. “tell us once”).

Over a period of time, the Register of Names and Addresses will therefore become the central authoritative source of basic information on which services are built, including e-government.

The Law was introduced at the same time as, and is administered alongside, the Control of Housing and Work (Jersey) Law 2012. The systems for administering these Laws were linked to the Social Security Department’s systems for administering the Social Security and Income Support Laws in July 2013. Subsequently, the Population Office moved to the Social Security building, enabling customers to access these services under one roof. This Regulation would enable a further Department to be linked to the register.

Medical purposes

If approved, these Regulations will enable the ‘registrable facts’ to be used by Minister for Health and Social Services, and persons acting on their behalf, for medical purposes.

- The definition of ‘medical purposes’ is as stated within the Data Protection (Jersey) Law 2005. It includes the purposes of preventative medicine, medical diagnosis, medical research, the provision of care and treatment, and the management of healthcare services, and thereby includes the broad range of health and social care services undertaken by the Health and Social Services Department.
- The use of the registrable facts by the Minister for medical purposes includes disclosure to health professionals and other persons who owe an equivalent duty of confidentiality, so long as those persons are acting on behalf of the Minister.

The registrable facts information would be processed within the Health and Social Services Department’s existing strict governance procedures.

Initially, the registrable facts will be used to support a number of population-based cancer screening programmes to the citizens of Jersey.

These are safe and effective evidence-based screening programmes designed to reduce serious illness and deaths from breast, cervical and bowel cancer. Strategic oversight for all cancer screening is provided by the Public Health Department and the Medical Officer of Health.

The Medical Officer of Health recommends that the Health and Social Services Department be permitted to utilise the demographic information held as the ‘registrable facts’ in order to write letters of invitation to men and women of the eligible ages for cancer screening.

To date, the Health and Social Services Department has been unable to do this for all Islanders who are eligible for cancer screening. This is because there has never been one comprehensive database within the Island holding names and addresses, details of gender, and dates of birth. Instead, Public Health officers have needed to use a number of advertising strategies – such as posters, media promotions, and awareness-raising banners, to increase Islanders’ awareness of the population-based cancer screening tests. These methods have been partially successful.

The Medical Officer of Health believes that because of the Department’s inability to directly invite eligible Islanders in a more systematic way, Jersey’s population-based screening programmes have not reached their full potential for preventing these forms of cancer.

Having access to the names, address, gender and date of birth information held within the names and addresses register would enable invitations to be mailed out to Islanders eligible for the 3 population-based screening programmes, which are –

- Cervical cancer screening – this is routinely recommended for women aged 25–64. The programme aims to detect and treat abnormalities which, if left untreated, could later develop into cervical cancer. In Jersey, one to 2 women still die each year from this preventable disease.
- Breast cancer screening – this is routinely recommended for all women aged 50–69. This programme aims to detect breast cancer at an early stage when there is greater chance of successful treatment. In Jersey, screening is

detecting, on average, cancers 50% smaller than those found amongst women who had not been screened.

- Bowel cancer screening – this programme is routinely recommended for men and women during their 60th birthday year. The flexible sigmoidoscopy test is designed to look for and remove bowel polyps. Once polyps are removed, they cannot develop into bowel cancer (this test is less effective in preventing cancer at earlier or later ages hence the specific age at which it is offered). Currently, 20 people die every year from bowel cancer in Jersey. Evidence confirms that, within 10 years, the screening programme will at least halve the annual incidence of this disease.

Work on using the registrable facts for population-based cancer screening programmes would begin immediately on approval of these draft Regulations.

In due course, these Regulations will also enable the wider use of the registrable facts; in particular, to support the Health and Social Services' electronic patient system known as 'Trakcare' –

- In their provision of care and treatment to patients, addresses held within Trakcare are used when mailing letters, such as appointments, to patients. Examples include pre-admission letters informing patients of dates for scheduled in-patient care (such as for elective surgery) or for out-patient care (such as clinic appointments). The Health and Social Services Department also uses Trakcare to populate addresses into letters and/or appointments for clients of social care services.
- The Health and Social Services Department would like to receive an electronic 'feed' from the names and addresses register so that any recent changes of address can automatically be updated in the Trakcare system. This would reduce the risk of appointment letters being sent to outdated addresses, and would increase the Department's efficiency in reducing the number of appointments at which patients do not attend.

The Health and Social Services Department already holds a wide collection of extremely sensitive data, and already has a number of governance procedures in place to ensure data is held securely and confidentially.

It is the policy of the Health and Social Services Department that all members of staff comply with the Data Protection Principles which are set out in the Data Protection (Jersey) Law 2005; and with Caldicott Principles, which arose from a review commissioned in 1997 by the UK Chief Medical Officer relating to the use of patient information within the UK National Health Service, which was chaired by Dame Fiona Caldicott. The Caldicott Principles have become the professional standards and best practice guidelines.

These include that when managing patient information, health service staff must justify the purpose(s) of using confidential information; that confidential information is only used when absolutely necessary; that the minimum amount of information is used to carry out the function; that access is on a strict need-to-know basis; that everyone with access to personal confidential information understands his or her responsibilities; and that every use of personal confidential detail is lawful. Caldicott also recommended that health services appoint a Caldicott Guardian, who has responsibility for ensuring that confidentiality and best practice are enforced and maintained. In Jersey, this is the Medical Director, and day-to-day functions, such as training and advice, are delegated to the Information Governance team.

It should be clear that these draft Regulations relate to the registrable facts *only*, and do not provide any authority or permission in relation to more sensitive information.

The Information Commissioner has been consulted in the development of these Regulations and is content with their compliance with the Law.

Financial and manpower implications

The use of the registrable facts to support population-based cancer screening programmes will be undertaken by in-house resources within normal work schedules without additional costs. As to the broader financial and manpower implications of using the registrable facts to support the electronic patient system known as 'Trakcare', the costs of this are not yet determined, but do not arise directly from these Regulations – which enable rather than require this work to be undertaken – and will be considered as part of overall ICT programmes within agreed budgets.

Explanatory Note

These Regulations specify additional purposes for which the Minister for Health and Social Services may access the Register of Names and Addresses under the Register of Names and Addresses (Jersey) Law 2012 (“Law”).

Regulation 1 defines “medical purposes” in similar terms to the way that term is defined in Schedule 3, paragraph 8 to the Data Protection (Jersey) Law 2005.

Regulation 2 allows the Minister for Health and Social Services to use any registrable fact on the Register for medical purposes. “Registrable facts” are defined under Article 2(8) of the Law to mean an individual’s name, address, date and place of birth, date of arrival in Jersey (if not Jersey born), gender and social security number.

Under Article 5(8) of the Law, the “use” of a registrable fact includes its disclosure. *Regulation 2* also provides that the Minister may disclose registrable facts to a health professional. A “health professional” is defined in *Regulation 1* to mean, in effect, doctors, dentists, pharmacists, pharmacy technicians, opticians and health care workers registered under the relevant Jersey legislation. Disclosure may also be to a person who owes an equivalent duty of confidentiality. In either case, disclosure is on condition that the person uses the registrable facts for medical purposes and that such use is in the course of the person acting for or on behalf of the Minister for Health and Social Services.

Regulation 3 sets out the title of these Regulations and provides that they will come into force 7 days after they are made.



Jersey

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Arrangement

Regulation

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Jersey

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Made [date to be inserted]
Coming into force [date to be inserted]

THE STATES, in pursuance of Articles 5(2) and 8 of the Register of Names and Addresses (Jersey) Law 2012¹, have made the following Regulations –

1 Interpretation

In these Regulations –

“health professional” means a person who is registered under any of the following enactments –

- (a) Medical Practitioners (Registration) (Jersey) Law 1960²;
- (b) Dentists (Registration) (Jersey) Law 1961³;
- (c) Pharmacists and Pharmacy Technicians (Registration) (Jersey) Law 2010⁴;
- (d) Opticians (Registration) (Jersey) Law 1962⁵;
- (e) Health Care (Registration) (Jersey) Law 1995⁶;

“medical purposes” includes any of the following –

- (a) preventative medicine;
- (b) medical diagnosis;
- (c) medical research;
- (d) the provision of care and treatment;
- (e) the management of healthcare services.

2 Access to the Register by the Minister for Health and Social Services

- (1) The Minister for Health and Social Services may use any registrable fact for medical purposes.
- (2) For the purposes of paragraph (1), “use” includes disclosure of any registrable fact to –
 - (a) a person who is a health professional;

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- (b) a person who, in the circumstances of the disclosure, owes a duty of confidentiality equivalent to that which would arise if that person were a health professional,

provided that the disclosure is on condition that the use by that person of the registrable fact is for medical purposes and that such use is in the course of the person acting for or on behalf of the Minister for Health and Social Services.

3 Citation and commencement

These Regulations may be cited as the Register of Names and Addresses (Access for Medical Purposes) (Jersey) Regulations 201- and shall come into force 7 days after they are made.

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- ¹ *chapter 15.660*
 - ² *chapter 20.600*
 - ³ *chapter 20.100*
 - ⁴ *chapter 20.770*
 - ⁵ *chapter 20.750*
 - ⁶ *chapter 20.300*