

# Julian's Key Hospital Procedure

## Applicable to:

All health staff, particularly:

- Record management and scanning staff
- Emergency Department Staff
- Nurse Navigators
- Nursing staff conducting hospital admission or pre-admission assessments
- All staff and services who work with consumers with:
  - aphasia, speech or communication difficulties
  - nasogastric or PEG feeding requirements
  - persistent mental illness which impacts on psychosocial function (psychosocial disability)
  - neurological conditions (seizure conditions, strokes, ABI, spinal injury, MS)
  - newly acquired disability and rehabilitation settings (stroke, ABIs, spinal injury)
  - permanent cognitive impairment (intellectual disability, Autism, dementia)
  - profound hearing or vision loss.
- Staff involved in strategy and planning for the HHS.

## Purpose

This document has been developed to provide HHS guidance on how to implement Julian's Key across their care settings followed by the supporting information.

Queensland Health is undertaking a trial to address system level barriers to patient experience, service access and coordination. The use of Julian's Key Health Passport (Julian's Key) will be trialled for a 12-month period among people with intellectual disability that access health services at Ipswich and Logan Hospitals.

## What is Julian's Key?

Julian's Key is a communication tool that can help provide holistic, person-centred, quality care to people with disability and chronic health conditions. The tool was designed to assist people to communicate their specific disability support and health care needs to staff in hospitals; in a convenient and accessible format.

Julian's Key is available via mobile application (phone or tablet), fillable PDF or paper-based format.

Utilising the information in Julian's Key will assist health staff to understand a patient's needs and preferences. It may also help to reduce a person's length of stay in a health facility and improve patient outcomes.



## Benefits to consumers and carers

- Enables people to be more involved in their care
- Communicates information to multiple staff.

## Benefits to health staff

- Assists in providing person-centred care
- Assists in understanding a person's health care needs
- Improves hand-over communication between staff
- Reduces behavioural incidents
- Assists the organisation to demonstrate complex care planning for accreditation or legal processes.

## Procedure

### On consumer admission or presentation

Staff to ask if the person has any care documentation such as those listed below and if they are happy to share it:

- Recording National Disability Insurance Scheme (NDIS) participant status in HBCIS
- Positive Behaviour Support Plans
- Disability care summaries (including Julian's Key Health Passport)
- Advanced Care Directives
- Statement of Choices
- Enduring Power of Attorney.

Julian's Key will alert clinicians to the presence of documents such as the Advanced Care Plan or Enduring Power of Attorney, but it does not replace these documents.

Services should consider amending existing procedures to prompt staff to ask for Julian's Key and similar disability care plans or Positive Behaviour Support Plans on admission. These documents can provide valuable insights into complex care planning. This is particularly relevant to all services involved in hospital admission:

- Pre-admission clinics
- Emergency Departments
- Wards that the person is being admitted to.

### Consumer controlled documentation

- The consumer or carer owns their copy of the Julian's Key Health Passport. They decide on the information that goes in the passport and who they share it with.
- Julian's Key remains the property of the individual and should remain in the person or the carer's possession once information has been used. Consumers may choose to share the document with staff when they attend health services.
- Julian's Key should not be kept on file once a patient has been discharged.
- If you have suggestions on how this information could be stored or used more effectively, please consider this as part of your response during the formal evaluation.

- Julian's Key is designed to assist staff with the process of assessments, examinations and care planning. Julian's Key should be treated as additional/supplemental information - it does not replace the need for routine assessment and care.
- Staff should be aware that the information in Julian's Key is consumer-reported information and it may become out of date. Routine practice must be followed to confirm critical information with verified sources (HBCIS, Medical Records, GP records) and usual assessment processes.

### Accessing the information

Patients can access the Julian's Key passport in different formats; mobile app (installed on their phone or tablet), fillable PDF or paper based.

When a consumer presents to hospital, you may ask:

- if you can read the information in the app. The patient can only send a copy of their completed Julian's Key Passport within the app to the email address they registered with. This can then be forwarded on to another email address, as needed.
- for the PDF to be emailed. If you are not comfortable sharing your direct email, determine if your service has an email address which can receive consumer information.
- for a copy of the paper version.

### Clinical documentation

Julian's Key is a form of consumer-reported information. Consumer information from Julian's Key should be documented using the same processes as verbal consumer information. Use your standard processes to document information from Julian's Key, the same way you would document patient discussions and verbal disclosures.

Clinical documentation practice may vary but you may document via case notes or ieMR updates and reference the name of the document "Julian's Key Health Passport provided on <<insert date>>".

*Note: Julian's Key is one source of consumer care information. You should use whichever clinical sources are most relevant and reliable. For example, always use someone's formal medication records if available.*

### Scanning and storage

Julian's Key should not be scanned into ieMR or kept in a permanent patient record. Julian's Key is a consumer-owned document and should be returned to the consumer before discharge. Julian's Key is a living document and is likely to be updated between presentations to health services.

### Complex care planning

Content from Julian's Key may be particularly relevant for complex care planning. Especially information about:

- behaviours of concern, positive behavioural support needs, fear and distress
- communication and comprehension
- clinical risks such as falls, swallow and aspiration risk
- consumer/carer partnerships and legal decision-making
- nursing care: hygiene and meal support
- physical support needs for hoisting, transfer and mobility

- discharge requirements, community care and related community services (i.e. NDIS).

### On discharge

The information a consumer enters into Julian's Key (mobile application, PDF or paper-based form) is owned by them and will not be kept on file once a person has been discharged, or disclosed to other parties without their consent, unless required by law.

On discharge, the health staff:

- will return paper copies of Julian's Key to the owner.
- may want to let other care providers know about Julian's Key or other relevant care documents.

## Consumer involvement/considerations

Julian's Key was developed by West Moreton HHS following the death of a patient with disability; Mr Julian Klass (in 2011).

Julian's Key was developed on the premise that when health practitioners have access to updated patient information, quality and continuity of care can be optimised, and the patient experience can be enhanced. Julian's Key enables improved, person-centred care, to consumers facing challenges when engaging with the health system.

## Monitoring and evaluation

Any issues encountered with Julian's Key should be reported in RiskMan Incident Reporting System.

Consumer complaints and compliments relating to the use of Julian's Key, should be referred to Consumer Liaison Services.

Any significant issues requiring an escalation should be reported to the State-wide Project Team, via:

- Email [Julian'sKeyTrial@health.qld.gov.au](mailto:Julian'sKeyTrial@health.qld.gov.au)
- Phone **(07) 3708 5601**

## Staff support resources

- [ABLEx Online Training](#) can be accessed for free with optional paid access for additional course assessment materials and certification. All courses in the ABLEx series are self-paced and suitable for professionals, families and others who are interested in intellectual disability health issues.
- [Queensland Centre for Intellectual and Developmental Disability \(QCIDD\)](#) has consumer and health professional resources about working with people with intellectual or developmental disability.
- [Queenslanders with Disability Network \(QDN\)](#) has consumer resources for people with disability.
- [Disability Awareness: Inclusion is within everyone's ability](#) by Department of Communities, Disability Services and Seniors.
- Queensland Health's [Information for people with disability](#)

- [The Essentials](#): from New South Wales - to guide and resource health service staff and other service providers to better understand and meet complex and multiple health needs of people with intellectual disability and their carers.

## Definitions

- **Carer:** a person who provides unpaid care for someone else – often a family member or close friend.
- **Disability:** a permanent or long-term (more than six months) condition – such as an illness, injury or syndrome – which impacts on function/ability and results in a need for support (equipment, modification, care) for activities of daily living. In an unsupportive physical or social environment, a person may experience economic, social and personal participation restrictions.
- **National Disability Insurance Scheme (NDIS):** a national insurance scheme which provides Australians with disability the support and services they need to participate in community and live their lives.
- **Person-centred care:** care that is respectful of, and responsive to, the preferences, needs and values of the individual patient. It involves seeking out and understanding what is important to the patient, fostering trust, establishing mutual respect and working together to share decisions and plan care. Click [here](#) for more information.
- **Positive behaviour support:** support provided to a person with behaviours of concern; which maximises their wellbeing and autonomy and manages social and environmental triggers. [Positive behaviour support](#) is a preventative approach which minimises and eliminates restrictive practices.
- **Restrictive practices and restraint:** restraint is the restriction of an individual's freedom of movement. It includes mechanical restraint, physical restraint, and chemical or pharmacological restraint and the use of seclusion. Restrictive practices should be minimised and where possible eliminated under the [NSQHS Accreditation Standards \(Standard 5\)](#).
- **Support worker:** a paid worker who provides support and care for someone else. For example, a disability support worker funded via the NDIS.

## Frequently asked questions

- **Do all people with disability need to complete Julian's Key?**  
No. It's an option which consumers can choose to use, or health staff can offer.
- **Is Julian's Key only for people with disability?**  
No. Anyone who has difficulty remembering or communicating their care needs is welcome to use Julian's Key. For example, an older person with dementia.
- **What if the clinician is aware that some of the information is out of date?**  
The clinician is not responsible for updating the document, as it's owned by the consumer. The clinician may want to recommend or suggest to the consumer that they update it.
- **Can Julian's Key be used at any hospital?**  
A patient can present with a Julian's Key Health Passport to any hospital or health service (GP, private health practitioner, diagnostic imaging etc).

## Document information

REFERENCES AND LINKS		
<ul style="list-style-type: none"> <li>• <a href="#">Queensland Anti-Discrimination Act (1991)</a></li> <li>• <a href="#">Queensland Human Rights Act (2019)</a></li> <li>• <a href="#">National Safety and Quality Health Service Standards:</a> <ul style="list-style-type: none"> <li>o Standard 2: Partnering with consumers</li> <li>o Standard 5: Comprehensive Care</li> </ul> </li> </ul>		
KEY WORDS ( <i>for searching on QHEPS</i> )		
Julian's Key	Disability	Complex Care
Health passport	Restrictive practices	Behaviour
Person-centred care	Cognitive impairment	
STAKEHOLDERS CONSULTED		DATE ENDORSED
AMENDMENTS FROM PREVIOUS VERSION		
AMENDMENTS		
Nil: new procedure.		