



The Royal New Zealand
College of General Practitioners
Te Whare Tohu Rata o Aotearoa



Child and Adolescent Health: Patient Portals, Health Information and Disclosure.

Guidance for general practice



GP

Heart of the community
Kāinga Tupu

Acknowledgements

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Feedback welcome

The project group welcomes your feedback on the usefulness of this resource. Any comments are invaluable to future revisions in this evolving field of health care. Please send you comments to policy@rnzcgp.org.nz.

Legal disclaimer

This resource is intended to provide guidance for general practice and should not be relied on as legal advice. For specific concerns about cases, please refer to relevant legislation and/or seek independent legal advice.

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Foreword

Patient portals have changed the way that we interact with our patients. They have the potential to allow patients and general practice teams to interact in a more meaningful way. We all know the importance of the doctor–patient relationship, and patient portals have the potential to deepen that relationship to create better patient outcomes.

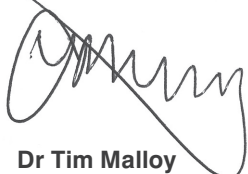
Evidence to date finds that most patients are enthusiastic about having the opportunity to access their health records online and use services such as booking visits or requesting repeat prescriptions. My own experience is that they are also beneficial to the practice, with a reduction in the number of phone calls and text messages that I receive.

However, providing a patient portal can also present a challenge, particularly when it involves adolescents. As young people age, they become better able to understand health information and to make their own decisions about their health care. This development comes with an increased expectation – and right – that we will respect and protect their confidentiality and privacy. You might have set up a patient portal for a 10-year-old that gives her parents the ability to access her health information on her behalf, but that arrangement is unlikely to be appropriate when that 10-year-old grows into a 15-year-old who comes to you to discuss her alcohol consumption.

The ethical duties and legal requirements that apply in situations like these can seem complicated, and so the College has worked with others in the sector – including the Ministry of Health and the Office of the Privacy Commissioner – to develop this guide to help general practitioners (GPs) to understand what is expected of them.

Because the expectations of you can be complex, we have tried to provide case studies that provide you with guidance in most of the common scenarios that might arise. The guide is not definitive, because not all adolescents mature at the same rate – we have all met 15-year-olds who are more or less capable of making important decisions about their lives and health care than their peers. The guide is also not expected to be something that you need to read and memorise.

Decisions about access to records usually do not need to be made quickly. If you face a question that you cannot answer immediately, pause the conversation and – once the patient has left your office – pull this guide from your shelf (or, more likely, our website) and review the [flowchart](#) on page 15. Don't be rushed into an answer, and particularly when you are required to consider the competence of a patient, take your time to assess the options and decide on your course of action. I hope you find this guide useful.



Dr Tim Malloy
President

SUMMARY

Portal access to health information of young people

Patient portals provide new opportunities for patients, including children and adolescents (young people), to access their health information and to interact with their general practice team. The following table provides a summary of the key factors that need careful consideration when determining the provision of portal access to the health information of young people.

Determining portal access to the health information of young people	
A young person's right of access to their health information	A young person has a legally enforceable right of access to their health information unless withholding grounds apply (eg disclosure would be contrary to their interests or would prejudice physical or mental health).
Appropriateness of providing portal access. Consider:	<ul style="list-style-type: none"> ■ The young person and their environment eg Are they a vulnerable young person? Are they able to keep safe? ■ The nature of the health information eg the young person's interests; the complexity, extent and sensitivity of the information ■ The individual's preferred form of information eg paper based, electronic or verbal. <p>As young people develop, their capacity to make their own medical decisions increases. Parents/guardians do not have an automatic right to all information about their mature young people – the young person's views on disclosure of health information should be listened to and considered. Young people who are sufficiently competent to make their own medical decisions are generally entitled to confidentiality and information privacy.</p> <p>Competence, for the purposes of consent, is determined by:</p> <ul style="list-style-type: none"> ■ age (ie 16 and older under the Care of Children Act 2004), OR ■ level of understanding (for those under 16, <i>Gillick</i> competence).
Portal access to the health information of a young person aged 16 years and over (where appropriate)	<ul style="list-style-type: none"> ■ Set up a patient portal as for an adult. ■ Parents and guardians have no special right to access their young person's health information once they turn 16.
Portal access to the health information of a young person aged under 16 years (where appropriate)	<p>SCENARIO 1: A young person, assessed as competent, first requests access to their health information via a portal.</p> <p>➔ Set up a portal taking into account the young person's wishes about disclosure of health information.</p>
	<p>SCENARIO 2: A young person already shares access to their patient portal with their parent.</p> <p>➔ Consider restricting a parent's access on a case-by-case basis, taking into account the young person's circumstances, including their competence, when:</p> <ul style="list-style-type: none"> ■ the young person requests withholding information from their parent or guardian, OR ■ a clinical situation arises that necessitates a review of shared portal access (eg involves sensitive information).

Determining portal access to the health information of young people	
Parental access to the health information of their young person under 16 years	<p>A parent or guardian has a right to access the health information of their young person under 16 years, except where contrary to the young person's wishes or interests or where another withholding ground applies.</p> <p>Factors to consider in withholding information include:</p> <ul style="list-style-type: none"> ■ the young person's maturity and understanding ■ the nature of the health information (eg sensitive and personal or about another individual) ■ the young person's health condition ■ whether access would harm the young person's physical or mental health ■ the young person's views on disclosure ■ the purpose for accessing the information ■ the young person's living arrangements ■ the relationship between the young person's parents and any custody arrangements ■ parental involvement in assisting with the provision of health care.
Options when setting up portal access to the health information of a young person aged under 16 years	<p>Depending on the circumstances, set up a patient portal for:</p> <ul style="list-style-type: none"> ■ only the young person who is assessed as having sufficient maturity and understanding (<i>Gillick</i> competent), OR ■ both the young person AND parent(s) or guardian(s) as shared portal access, OR ■ only parent(s) or guardian(s) (usually for infants and young children).
Options when restricting parental portal access to the health information of a young person under 16 years	<ul style="list-style-type: none"> ■ Set up a patient portal for the competent young person only, OR ■ Set up a patient portal with shared access for the parent and young person, and upload only non-confidential health information from the patient management system (PMS) to the portal. The remaining information may need to be provided by other means.
Preparing for a shift of control over the portal from parent/guardian to young person	<p>Start a conversation in early adolescence to foster acceptance of a future shift of control over the portal from parent/guardian to young person. Have discussions with the young person and their parent or guardian about confidentiality and explain that health information will be shared or withheld depending on circumstances, which includes the young person's views on disclosure and their interests.</p>

Introduction

Patient portals provide new opportunities for patients to access their health information and to interact in a more meaningful way with their general practice team. While many adults in New Zealand have signed up for a patient portal, less attention has been given to their use in young people. Providing portal access to the health information of young people can present challenges, particularly with regard to confidentiality and privacy considerations.

This is an evolving area of health care. This resource discusses the relevant principles and provides general guidance for general practice. Case studies are used to examine potential issues when providing portal access to the health information of young people. The resource does not intend to be prescriptive but rather raises matters for practices to consider when developing policies for their own practice context.

Implementing patient portals changes the status quo by providing patients with timely online access to health information and a means to communicate and interact electronically with their general practice team. This includes the ability for patients to securely message their practice, book appointments, check laboratory results and request repeat prescriptions via the portal. Furthermore, portals may allow patients to access their medical history, including clinical diagnoses, allergies, immunisations and visit notes. Importantly for young people, patient portals may help to enable them to participate in their own health care.

International research has shown that parents and young people generally support the use of patient portals in the health care of young people. Parents perceive portals as beneficial for managing their young person's health, especially chronic conditions.^{1,2} Portals have been found to facilitate communication between parents and health care providers, reduce anxiety, provide convenience and offer reassurance.³ Benefits for young people include having control of their own health care; the ability to access their health care providers, to seek information from a known reliable source and to make appointments;⁴ improving health literacy and ongoing care for chronic conditions;⁵ and enhancing health care quality.⁶

While patient portals are a tool used to improve the quality of health care, providing access to electronic clinical records does not change a GP's obligations around patient confidentiality and privacy of health information.

Good communication between GP and the young person and their parents is key.

TERMINOLOGY

For the purposes of this resource, the term **young people** (or **young person**) is used to refer to children and adolescents from birth to 18 years. The term **parent** includes those who have guardianship* of a young person.

In this document, **shared portal access** refers to the situation where both the young person and their parent(s) have access to the patient portal of the young person. This includes access to the young person's clinical record as well as to other features such as booking appointments and secure messaging. There are various mechanisms for providing shared portal access, depending on the type of portal used (eg both young person and parent use the same username and password to gain access, or both young person and parent have access via their own accounts).

Patient portals may help to enable young people to participate in their own health care.

* See Part 2 of the [Care of Children Act 2004](#) on guardianship and care of children.

Patient portals and health information

Ethical duties and legal requirements

Informed consent and competency

Parents are, for the most part, responsible for the health care of their young people. As young people develop, their capacity to make decisions and take responsibility for their health increases gradually. For the purposes of consent to treatment, capacity or competence is decided either by age (ie 16 and older under the Care of Children Act 2004[†]) or, for those under 16 years, their level of understanding of proposed treatment. The understanding-based approach is situation specific and determined on a case-by-case basis ('*Gilllick* competency' test). GPs need to carefully assess a young person's level of maturity and understanding of the nature and implications of proposed treatment, having regard to the individual's best interests and wishes and the wishes of their parents. Consent to treatment is closely aligned to confidentiality and health information privacy.

Even if a young person is not sufficiently mature to give a valid consent, they have a right to receive appropriate information (Right 6(2) of the Code of Health and Disability Services Consumers' Rights). The information should be given to the young person at the level of their understanding.⁷

Further discussion on informed consent is set out in [Appendix 1: Legal considerations](#).

Trust and confidentiality

Trust is a central feature of the doctor–patient relationship. Patients often have to divulge sensitive personal information in order to obtain treatment. Young people, particularly teenagers, might not want their parents to know certain information. They may find it difficult to confide in anyone, even their GP, and will do so only if they can trust their GP not to breach their confidence.⁸ Notably, young people are more likely to forgo needed health care if they are worried about privacy and confidentiality, especially for sensitive medical issues such as emotional health, sexual health or substance use.^{9,10} However, young people should be made aware that, while a GP might not disclose information to their parents, specific legislation may require disclosure without their consent.

In responding to a parent's request to access their young person's health information, GPs are faced with the competing interests of their ethical duty of confidentiality to their patient, who might not be competent to consent to treatment, and a parent who wants or needs to know about their young person's clinical situation. Trust, confidentiality and privacy need to be taken into account when deciding whether or not to disclose information.⁷

† Section 36 of the [Care of Children Act 2004](#). Of note, under s 38 of the Care of Children Act, a female child 'of whatever age' may consent to or refuse consent to an abortion 'as if she were of full age'.

Young people are more likely to forgo needed health care if they are worried about privacy and confidentiality, especially for sensitive medical issues such as emotional health, sexual health or substance use.^{9,10}

Parents do not have an automatic right to all information about their mature young people.

An understanding-based approach

Parents do not have an automatic right to all information about their mature young people. The Health Information Privacy Code 1994 (HIPC) adopts an understanding-based test for the ability to exercise rights under it, recognising that young people have a degree of autonomy that does not rely on a certain age. Just as the views of a mature young person must be listened to and taken into account in respect of treatment, so should their views be ascertained and considered in respect to disclosure of personal information.⁸ In practice, however, young people are likely to involve their parents in their health care in most situations.

In many cultures, decision-making about young people involves their whānau and extended family networks, as well as the young person and their parents. GPs need to be aware of cultural needs and discuss them with the young person. Consider seeking guidance on cross-cultural communication from a cross-cultural expert experienced in youth development.

The Health Information Privacy Code applies

Registering to the patient portal will provide access to the health information uploaded from the patient management system (PMS) to the portal. This might include a portion of the young person's clinical record agreed on by the GP and young person and/or parent where needed or appropriate. When considering requests to access health information via a patient portal, the HIPC applies as it would to requests for access by other means. It may be appropriate to provide the health information in another form (eg paper copy with a security reminder) if there is good reason why portal access is not in the interests of a young person under 16 years (even where access by portal has been explicitly requested).

A need for careful consideration

A GP's legal and ethical duties to young people and their parents underpin the need to make time for careful consideration when introducing patient portals and uploading health information.

College and Ministry of Health guidelines

The 2015 guidelines developed by The Royal New Zealand College of General Practitioners and the Ministry of Health¹¹ provide practical guidance on implementing patient portals. Guidance on accessing health information of young people is reproduced below.

A. Young people's access to health records

- All individuals, including young people, have the right of access to their own health information (rule 6 of the HIPC).
- If a young person makes a request for information via a portal or otherwise, the practice is obliged to consider the request as they would for an adult. Considerations include the following:
 - The GP may use discretion about the appropriateness of the information to be uploaded.
 - It might also be appropriate to ensure someone is able to assist the young person to interpret the information and to answer questions.
 - General practices may refuse to give access if, in the doctor's judgment, the disclosure of the information would be against the young person's interests.

GPs need to be aware of cultural needs and discuss them with the young person. Consider seeking guidance on cross-cultural communication from a cross-cultural expert experienced in youth development.

B. Parent/guardian access to health records

- For young people under the age of 16, except where contrary to the young person's wishes or interests, a parent or guardian has a right to access the young person's health information. The portal can facilitate that access. Considerations include the following:
 - As with any request for access, general practices are obliged to take reasonable precautions to ensure the person making the request is properly authorised to obtain the information.
 - In the case of very young children, access may be granted unless there is a reason to withhold the information from a parent as the young person's representative.
 - Judgment should be exercised where older young people in particular do not wish their parents to know sensitive personal information (see further discussion below).
- Matters to consider in withholding information might include:
 - the nature of the health information (eg sensitive, personal information or information about someone else)
 - the young person's health condition
 - whether access would harm the young person's physical or mental health
 - the views of the young person
 - the reason for accessing the information
 - the rights of access that the parent has as the young person's representative
 - the young person's living arrangements
 - the relationship between the young person's parents and any custody arrangements
 - parental involvement in assisting with the provision of health care.
- Once young people turn 16, their parents or guardians have no special right to access their health information. One consideration is that:
 - GPs may give health information to a principal caregiver or near relative where it is not practical or desirable to get the patient's permission (eg if the patient is very unwell or not competent) and the patient has not vetoed the disclosure.

Further discussion on the relevant law can be found in [Appendix 1](#).

Portal access

A suggested framework for considering requests

When portal access is requested, consider two issues: disclosure of health information and access via a patient portal.

A. Disclosure of health information

In approaching requests for access to health information of a young person, consider the following:

- Does the law authorise or require the information to be made available? Remember that young people have the right of access to their health information unless withholding grounds apply (eg disclosure would be against their interests).
- Is the young person competent for the purposes of consent to treatment? Either:
 - a. They are 16 years or older (in accordance with the Care of Children Act 2004), or
 - b. They have sufficient maturity and understanding of the nature and the implications of the proposed treatment ('*Gillick* competency' test).
- For a young person aged 16 years or older, their parents have no special right to access their health information (in accordance with the Care of Children Act 2004).
- For a young person assessed as *Gillick* competent, ask whether they opt to share their health information with their parent(s).
- For young people under 16 years, do any withholding grounds authorise the refusal of a parent's request to health information of their young person? For example: is disclosure contrary to the young person's wishes or interests? (s 22F of the Health Act 1956 and rule 11(4) of the HIPC).

If no withholding grounds apply, the information must be released to a parent on their request.

B. Portal access to health information

In relation to portal access to the young person's health information, consider:

- Is it appropriate to provide access to the health information via a patient portal? Consider:
 - the user and their environment (eg is the young person vulnerable? Are they able to keep safe?)
 - the nature of the information (eg extent and complexity of information; is release against young person's interests? Is it sensitive?)
 - the individual's preferred form of information (eg paper based, electronic or verbal).

- Who will have portal access to the clinical records? (See discussion below.)
 - Only the young person who is aged 16 and over or who has been assessed as having sufficient maturity and understanding (*Gillick* competent), or
 - Both young person AND parent(s) (shared portal access), or
 - Parent(s) only.

Table 1. Summary of portal access for the young person and parent

Patient's age	Information of a young person	Options for setting up a patient portal
16 years and over	Parents have no special right to access the information. The young person can choose to give an adult proxy access to their portal.	➔ Set up a patient portal as for an adult.
Under 16 years	<p>STEP 1: Portal access for the young person</p> <p>Young people have the right of access to their health information (unless withholding grounds apply).</p> <ul style="list-style-type: none"> ■ Does the young person have a sufficient level of maturity and understanding of the proposed treatment (<i>Gillick</i> competence)? ■ Consider limiting parental access on a case-by-case basis, taking into account the young person's circumstances, including their competence, when: <ul style="list-style-type: none"> (a) he or she makes a request for some or all of their health information to be withheld from their parent, or (b) a clinical situation arises that necessitates a review of portal access (eg involves sensitive information). 	<p>Where you have assessed a young person as competent and decided to withhold some or all of their health information from their parent(s), either:</p> <ul style="list-style-type: none"> ➔ provide portal access for the competent young person only, <p>OR</p> <ul style="list-style-type: none"> ➔ set up shared portal access for the competent young person and parent, and restrict uploading a portion of the health information from the PMS to the portal. (The remaining information may need to be provided by other means.)
	<p>STEP 2: Portal access for the parent</p> <p>Parents have full access to all information unless withholding grounds apply.</p>	<ul style="list-style-type: none"> ➔ Set up shared portal access for both parent and young person, <p>OR</p> <ul style="list-style-type: none"> ➔ Set up a patient portal with access by parent only.

Control of a patient portal

While parents would normally control the portal of their infant or young child, the age at which control may shift to an adolescent is not fixed. An underlying reason for this is the varying rates of maturity between early and late adolescence. One young person aged under 16 years might be assessed as having sufficient capacity to consent to care without parental involvement before another young person of the same chronological age.

This paper does not attempt to define a minimum age at which control of the patient portal may shift to the young person under 16. This is consistent with the New Zealand law on informed consent and the HIPC, which recognise that young people have a degree of autonomy not reliant on a certain age. Young people who are sufficiently competent to make their own health care decisions are entitled to confidentiality and information privacy with exceptions broadly similar to those for adults (eg where release is authorised by the individual, or where a failure to release may present a serious threat to the individual or another).

Developing health literacy is an important aspect of providing portal access to young people. Portals can enable young people to improve their health literacy by providing easy access to key health information and a way to communicate electronically with health care providers. However, it is important to ascertain the level of understanding of the young person as well as their parent(s) and ensure that health information is presented in a way they understand.¹²

Two scenarios to consider for young people aged under 16 years:

1. A young person, assessed as competent, first requests access to their health information via a portal.
2. A young person already has shared portal access with their parent and a situation arises where he or she may wish to withhold all or certain aspects of their health information from their parent(s).

Scenario 1: A young person, assessed as competent, seeks portal access

Where a young person seeks portal access, assess their level of maturity and understanding. A young person under 16 years attending alone (ie no supporting adult in the waiting room) is likely to be *Gillick* competent. Ask whether they wish to withhold health information from their parents. If appropriate, set up a patient portal for the *Gillick* competent young person only; or, if they opt to share health information, set up shared portal access for the young person and their parent.

Where a competent young person refuses to allow disclosure of information to their parents, the GP may still receive information from the parents and give general, non-personal information. The GP should also work with the young person to understand their reasons and discuss opportunities for limited disclosure.

It is important to encourage young people, particularly those with more serious or complex health issues, to seek support from a trusted family adult where appropriate and to share information about decision-making on health matters with the adult they are closest to.

Portals can enable young people to improve their health literacy by providing easy access to key health information and a way to communicate electronically with health care providers.

Scenario 2: Transitioning control of a patient portal

For young people already with shared portal access, decisions about limiting parental access should be made on a case-by-case basis, taking into account the young person's circumstances, including their competence, when:

- a. the young person requests that you withhold information from their parent(s), or
- b. a clinical situation arises that necessitates review of portal access (eg personal, sensitive information).

At these points, the GP, together with the young person, should reassess shared portal access, and where appropriate, shift control of the patient portal to the competent young person.

Clinical situations that might necessitate a review of portal access include:

- diagnosis and treatment of a sexually transmitted infection
- contraception
- medical care related to the prevention of pregnancy
- pregnancy test
- ultrasound scan for pregnancy dating
- outpatient mental health services
- antidepressant for a young person undergoing confidential mental health care
- methadone for substance abuse withdrawal
- drug and alcohol misuse
- sterile pyuria in urinalysis
- information suggestive of risk taking (eg truancy, unprotected sex, smoking, drugs, alcohol)
- information on social factors (eg violence, poverty, homelessness, parental mental health, criminal activity).

Recording sensitive information about a young person who consults without a parent should also trigger discussions about continuing or discontinuing shared portal access.

Requests to limit parental access should be talked through with the young person so that their concerns are understood. Those with sensitive health issues should be encouraged to seek support from a trusted family adult where appropriate and to share information for decision-making on health matters with the adult they are closest to. Keep in mind the young person's best interests and their legal rights. Be open, particularly with older young people where parental consent to treatment will be sought. For example, while a young person may be competent to consent to seeing a dietitian, he or she may not be competent to consent to complex, high-risk surgery. Explain that information will have to be disclosed in order to obtain their parent's consent.

To pre-empt later problems around confidentiality and disclosure of health information, start discussions about portal access during early adolescence. Foster the acceptance of a future shift of control over the portal from the parent to the young person. Talk with the young person and their parent(s) about confidentiality and when information is needed or not needed to be shared. Discussing the benefits of shifting access to young people and promoting open communication between parents and young people may help to alleviate any parental concerns.

Keep in mind the young person's best interests and their legal rights.

Start discussions about portal access during early adolescence. Foster the acceptance of a future shift of control over the portal from the parent to the young person.

Discussions will be facilitated by normalising early on the practice of spending some time during a consultation seeing the young person alone. This promotes the idea that young people are able to access care independently and helps develop health literacy.

Understand cultural needs

For young people with collective cultural values, offer the opportunity to involve whānau and extended family networks in discussions, but note that patients might prefer to seek professional advice and information before consulting a relative and/or wider family.

It may be helpful to involve a youth health practitioner or Māori or Pacific health worker in these discussions, and it may also be necessary to provide the assistance of an interpreter. Guidance on cross-cultural communication can be sought from cross-cultural experts experienced in youth development (eg health workers, social workers, youth workers). Youth health practitioners – who are available by phone at school-based health services and Youth One Stop Shops – can provide information about cultural values and how best to support young people and to approach parents and relatives.

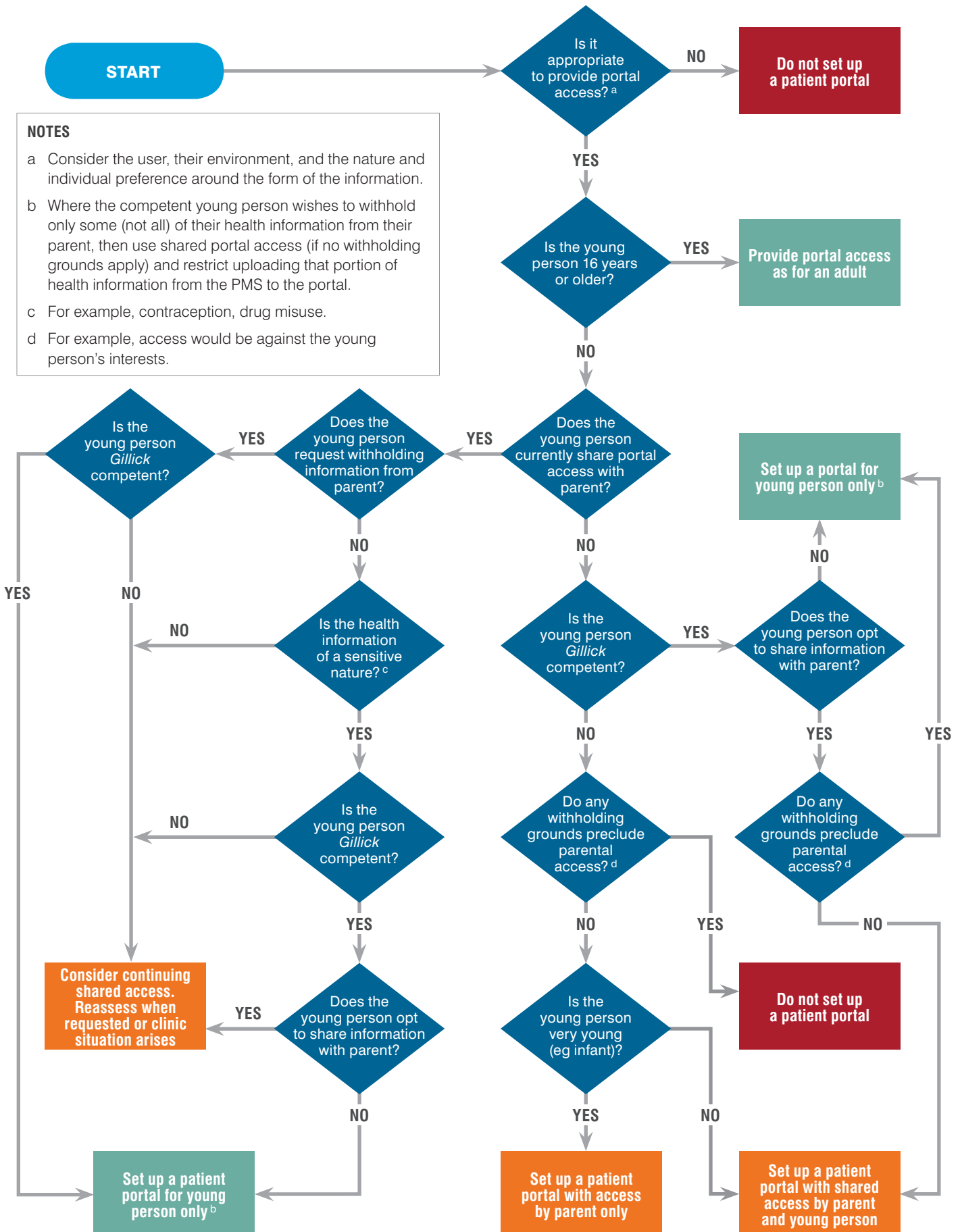
Flowchart: Determining portal access

The flowchart on page 15 (Figure 1) illustrates the main steps in the decision-making process for providing portal access to the health information of a young person.

The flowchart does not attempt to detract from the complexity of the process. It aims to complement the text in this document by highlighting key decision points. Each request for portal access will need careful consideration, taking into account the young person's circumstances. Good communication is crucial.

Figure 1. Key decision points when determining portal access to the health information of a young person

Should I provide portal access to health information of a young person?



NOTES

- a Consider the user, their environment, and the nature and individual preference around the form of the information.
- b Where the competent young person wishes to withhold only some (not all) of their health information from their parent, then use shared portal access (if no withholding grounds apply) and restrict uploading that portion of health information from the PMS to the portal.
- c For example, contraception, drug misuse.
- d For example, access would be against the young person's interests.

Setting up a patient portal in practice

The information below offers a starting point for practices to develop their own processes relevant to the patient portal used at their practice and is based on current versions of the software at the time of writing.

Setting up patient portals will differ depending on the PMS used by the practice, eg Medtech, MyPractice, ConnectMed, and it may be necessary to consult the practice's patient portal vendor for specific details.

A secure username (ie a unique email address) and password are required to set up a patient portal.

For some patient portals such as **ManageMyHealth**, the **Medtech** portal, a different email address is required for each individual with a portal. This keeps each person's clinical records separate. A portal may be set up in the young person's name with access granted to one or both parents. Parents who already have their own portal will need a secondary email address for their young person's account. To share portal access, both the young person and their parent(s) will need to use the young person's username (email address) and password to access the patient portal. The need to share log-in details arises from current limitations of system design.

For other portals, eg **Health365**, the **MyPractice** patient portal,[‡] parents who belong to the same practice as their young person are able to access their young person's clinical records through their own portal account. The general practice team can grant access to the clinical records of a patient's dependants if deemed appropriate. The health information of both parent and young person will appear in one account/view. If both parents are patients at the practice, each parent can be provided access to their young person's records. Extra care should be taken because it is easier to enable parental access in this manner. Young people will also need an email address to access their own records.

ConnectMed will work in a similar way, with parents being able to access their young person's information via the parent(s) own account(s) where the practice has granted access.[§] The practice will create an account at its discretion for a young person.

Portals are configured to an email address. Therefore, if a user forgets their password, they will need to request a new password which is sent to their email address. This means that anyone who accesses the email account will have portal access to the clinical records of the young person.

‡ Health365 can also be used with the Medtech PMS.

§ At the time of publication, ConnectMed aims to have functionality to add family members in 2017. This will be controlled by the practice via the practice portal app. Currently patients can book appointments on behalf of others (such as a young person) by manually typing in the patient's name.

Setting up patient portals will differ depending on the PMS used by the practice.

The young person and/or their parent(s) are able to access all information loaded onto the portal. Information that is marked confidential will not be uploaded from the PMS to the portal and will not be visible to the young person or parent(s). The implications of this should be explained to them. It may be necessary to consult the practice's patient portal vendor to ensure this is done correctly.

Where shared portal access is to be set up, ensure a young person understands that their parents will have access to their health information. It is safest for the young person and their parent(s) to decide together to register for a patient portal.

When limiting parental access, consider setting up a patient portal for the competent young person only. For young people with shared portal access, the practice team can disable or remove access for either or both parents, as appropriate. The young person should then safeguard his or her username and password.

When a practice suspends a young person's registration to the **ManageMyHealth** patient portal (such as when they leave a practice), the young person (and parent, if sharing portal access) will still be able to log on and see all previously uploaded data. However, they will not receive any further updates and will not be able to access the services offered by the practice. Further, as an account is linked to a user via a unique email address, access is controlled by whoever controls the email address in relation to changing passwords.

Practices using **MyPractice** can remove access to any dependant on request. This is instantaneous. There will be no ongoing access to any part of the clinical record.

It may be necessary to consult the practice's patient portal vendor to ensure information marked confidential is not uploaded from the PMS to the portal.

Case studies

CASE STUDY 1

A young person requests portal access to health information

Eleven-year-old Michael and his mother are regular patients at your practice. Michael makes a request for access to his personal health information via a patient portal. What do you do?

Michael has the right of access to his health information (rule 6 of the HIPC), and the patient portal can substantially facilitate this access. The information should also be disclosed to his parent(s) on their request, unless withholding grounds apply (section 22F of the Health Act 1956). In providing access to Michael, consider:

- whether the information is against Michael's interests – access may be refused if the disclosure is considered to be against his interests (s 29(1)(d) of the Privacy Act).
- the appropriateness of uploading the information to a portal – use discretion. It would be sensible to ensure someone can assist Michael to interpret the information and to answer his questions.
- Michael's preference on the form of information. Patients have the right to effective communication in a form, language and manner that enables them to understand the information provided (Right 5(1) of the Code of Health and Disability Services Consumers' Rights).

If there are no reasons to refuse Michael's request, Michael and his mother – if no withholding grounds apply – may be registered for a patient portal (in Michael's name) and have shared portal access to all or part of Michael's clinical records.

If Michael's mother is reluctant for the practice to grant portal access to Michael, Michael's best interests and his right of access to his health information are key considerations. Explain to her how the portal works and how it will directly benefit her and Michael. Brochures and other informational material may assist.

This would also be an appropriate time to start a conversation with Michael and his parents about a future shift of control over the portal to Michael as he moves into adolescence. Have discussions about confidentiality and when information is needed or not needed to be shared. Developing Michael's health literacy is also an important consideration.

CASE STUDY 2

Providing tamariki in a whānau with portal access

Hōri and Mere are married and both have their own patient portals using separate email accounts. They have six tamariki (children) aged 16 years, 14 years, 13 years, 10 years, and twins aged 7 years. All are patients at your practice. Mere asks you to provide the tamariki with portal access as well. What do you do?

In this case, consider whether granting portal access is appropriate and how it should be set up for each tamaiti (young person). Matters to consider for each tamaiti include:

- the rights of access that their parents have as their representatives
- their maturity and understanding (whether *Gillick* competent)
- the nature of the health information (eg sensitive, personal information)
- their health condition
- their views on privacy and confidentiality, including views on the disclosure of information
- whether disclosure of information is against their interests
- the relationship between their parents and living arrangements
- any custody arrangements or court suppression order
- their preference on the form of information.

For the 16-year-old, portal access may be set up as for an adult. The parents have no special right of access to their health information. However, the parents may request access to the health information and this should be considered under the Privacy Act 1993.

For the tamariki aged 7 and 10, their parents have a right to access their health information unless contrary to their wishes or interests. It is unlikely these tamariki

would want to withhold any of their health information from their parents. However, you should still talk this through and confirm it with the tamariki and Mere.

One option is to set up portal access for Mere only (as the tamariki representative with primary control of the account) or, alternatively, shared portal access for Mere and each tamaiti. Each tamaiti will need their own email address, which is their unique identifier for the portal. (For Health365, parents can access the clinical records of each tamaiti via their own account.)

The tamariki aged 13 and 14 may wish to keep certain aspects of their health information from their parents now or in the future. This should be discussed with the tamariki, taking into account the above considerations, including their level of understanding and maturity. Shared portal access could be set up for Mere and each tamaiti with all or some of the health information uploaded from the PMS to the portal. (The remaining information may need to be provided by other means.) Alternatively, portal access could be set up for each tamaiti themselves. Again, each tamaiti will need their own email address, which is their unique identifier for the patient portal.

CASE STUDY 3

A mature young person

Lauren is 15 years old, and you have known her since she was a baby. She is consulting you with her friend to discuss contraception. She has recently become sexually active, always with condoms so far.^{||} Her mother, who is a nurse, knows that Lauren has a boyfriend who is the same age but has told Lauren not to have sex. You have a good chat with Lauren about making safe choices with relationships, safe partying, and sexually transmitted infections. She has a good understanding of all this information. Currently, she has her period. After considering her choices, she chooses to start Depo-Provera. She asks you not to discuss her contraception and her sexual health consultations with her mother.

Two weeks later, Lauren and her mother come back to see you together because Lauren has a urinary tract infection. At this time, her mother asks if she and Lauren can be set up for shared portal access so they can access Lauren's clinical records and the urine test result. What do you do?

Consider the following factors:

- Lauren's maturity and understanding (whether *Gillick* competent)
- The nature of her health condition and the proposed treatment
- Lauren's views on treatment
- The nature of the health information (eg complexity, sensitive personal information)
- Lauren's views on confidentiality and privacy, including portal access to clinical records
- The rights of access that her mother has as Lauren's representative
- Whether disclosure of information is against Lauren's interests
- The appropriateness of setting up a patient portal.

Ideally, the issue of restricting parental access to Lauren's health information should have been raised earlier, such as when Lauren first consulted without a parent about contraception.

If not done already, raise the issue of parental access to health information. Ask Lauren about her views on privacy and confidentiality with regard to portal access to her clinical records. Confidentiality and privacy will also need to be discussed with Lauren's mother, including the appropriateness (or not) of providing shared portal access to Lauren's clinical records. Such discussions will be facilitated if the GP's normal practice has been to spend some time during consultations seeing young people alone.

If Lauren is assessed as having sufficient maturity and understanding to provide informed consent to care relating to contraception and sexual health, there would be no need to seek parental consent to this treatment.[†] Therefore, Lauren's mother will not need access to confidential information relating to contraception and sexual health for the purposes of providing informed consent. If Lauren chooses not to share information (or if disclosure is contrary to her interests), then the information may not be disclosed to her parents (rule 11(4) of the HIPC and s 22 F of the Health Act 1956). However, Lauren may still opt to involve her mother for support.

In Lauren's circumstances, you may decide to withhold some or all of her health information from her parent. Options include:

- Setting up a patient portal for Lauren only and providing Lauren's mother with the non-confidential health information by other means.
- Setting up Lauren and her mother for shared portal access to Lauren's clinical record and uploading only a portion of the information from the PMS to the portal (eg do not upload information relating to contraception and sexual health for her mother to view). It may be necessary to consult the practice's patient portal vendor to ensure this is done correctly.
- Not setting up portal access and providing the requested non-confidential information to Lauren's mother by other means (eg paper basis).

^{||} It is noted that sexual conduct with a person under 16 years is an offence under the Crimes Act 1961; however, this resource does not consider situations in which a doctor may be obliged to provide information that will breach confidentiality.

[†] In 1990, repeal of the section in the Contraception, Sterilisation, and Abortion Act 1977 that refers to young people under 16 years means that the supply of contraceptives to minors is now subject to the general rules governing treatment of minors.

CASE STUDY 4

Disclosing health information when parents are divorced

A couple in your practice have had a recent, acrimonious divorce. They have 50:50 shared care of their eight-year-old daughter, Frances, who has had frequent visits with recurrent tonsillitis. Frances' mother has portal access to the clinical records of Frances. Her mother has asked if you can prevent the father from having access to Frances' clinical records. Frances' father has just rung asking for portal access to the clinical records. What do you do?

Unless a court order states otherwise, both Frances' mother and father are entitled to access to Frances' health information, regardless of any custody or access arrangements (s 22F of the Health Act and rule 11(4) of the HIPC). The information must be released unless a withholding ground applies.

In deciding whether to withhold the information,** factors to consider are:

- whether or not it would be in Frances' best interests to disclose the information
- whether or not Frances wants the information to be disclosed
- Frances' health condition
- the nature of the health information
- the relationship between Frances' parents
- whether the disclosure would involve the unwarranted disclosure of the affairs of another individual.

If you decide that access to Frances' health information should be granted to both her mother and father, the options include the following:

- a. Setting up portal access to Frances' clinical records for both parents. This will depend on the type of portal used.
 - For Health365 (the MyPractice patient portal), where all individuals are patients at the same practice, then both parents may be granted access via their own accounts.
 - One of the main limitations of ManageMyHealth (the Medtech portal) is the inability to have multiple log-ins linked to a young person's patient portal. If both parents know the young person's username (email address) and password, then they both would have access to the young person's portal. However, even if parents share

the log-in details to a young person's portal, the parent in control of the email address will have control of the account (eg have the ability to reset the password at any time).

- b. Where it is impracticable for both parents to have portal access, then provide access to the health information through a paper-based mechanism either to:
 - (i) Frances' father (given that Frances' mother already has portal access), or
 - (ii) Frances' mother, and assign control of Frances' patient portal to her father, or
 - (iii) both parents, and close the patient portal.

There are benefits to both parents having portal access in this situation. It facilitates their access to timely health information about Frances. The portal also allows the parents to book appointments and order repeat prescriptions for Frances, with the associated financial implications. It is acknowledged that inherent practical challenges may arise in this situation because of the current limitation of some platforms for portals. Any decision about how to disclose the health information must be based on Frances' best interests, drawing upon the knowledge of her family circumstances.

An additional consideration is whether the clinical records uploaded to the patient portal contain mixed information about Frances and her father. This portion of mixed information may be withheld from Frances' mother if releasing it would involve the unwarranted disclosure of her father's affairs (s 29(1)(a) of the Privacy Act 1993). Thus, if one parent has portal access, it would be sensible to upload to the portal only the portion of the clinical record where the health information about Frances is not mixed with information about the other parent. The parents retain the right to access the remaining health information under the Privacy Act 1993.

** The withholding grounds are outlined in sections 27–29 of the Privacy Act 1993.

CASE STUDY 5

Portal access when parents are divorcing

Ben and Alex have an eight-year-old son, Samuel. They are all patients at the same practice and registered to ManageMyHealth. Ben's GP is Dr Smith. Alex and Samuel see Dr Jones. Both parents have portal access to their own clinical records. Samuel already has a patient portal set up, and Alex has been given control of Samuel's portal access. Until recently, Alex has shared that access with Ben.

Ben and Alex are now going through an acrimonious divorce. After shifting house, Ben rings the practice asking for access to Samuel's portal as Alex has changed the password. Ben no longer has access and Alex is not providing him with access to Samuel's health information. What would you do?

Your initial considerations on Ben's request for access to his son's records will be the same as if Ben asked for the information in paper or verbal form. Both Ben and Alex have a legally enforceable right to access to the health information irrespective of custody (s22F of the Health Act 1956) unless a court order applies. If there is no specific reason otherwise, it is likely that you would allow Ben access to Samuel's records.

The consideration now is the mechanism by which you allow access. Traditionally, you may have answered Ben's specific questions about Samuel's health information or supplied a printed copy of the clinical record. The patient portal allows ongoing access to Samuel's clinical record.

With ManageMyHealth (the Medtech portal), the current design means that 'control' can only be assigned to one person. Where both parents are cooperative, it would be reasonable to expect that they would share access credentials to the portal of their child (while one parent has ultimate control of it). However, in this scenario, the acrimonious nature of the relationship may mean that one parent – Alex or Ben – has primary control of the account, including portal access.

If you decide that both parents should still have access to Samuel's clinical record, the options include the following:

- a. Ask Alex to permit Ben to access Samuel's patient portal.
- b. Provide Ben with a paper copy of Samuel's clinical records.
- c. Assign Ben control of Samuel's patient portal. A practice can change the email address associated with an account.
- d. Close Samuel's patient portal and supply records to both parents on a paper basis.

Notably, Health365 (the MyPractice patient portal) would allow the practice to grant access to Samuel's records to both parents via their own log-in credentials.

There is no correct answer. Each option has benefits and risks that must be considered and applied to the unique situation. The options above may not be applicable if a court order is made. The fallback position is closing portal access. However, notably, portals can provide more than a means of accessing clinical records. Patients can book appointments, request repeat prescriptions and undertake secure communication with the practice.

In a similar scenario, eight-year-old Samuel does not yet have a patient portal set up, and Ben and Alex are going through an acrimonious divorce. Ben has rung the practice asking for access to Samuel's health information. What do you do?

In this situation it would be reasonable to not create portal access at this point in time. Ben (and Alex, if they so request) could be supplied with a paper copy of the clinical records (option (d) above).

CASE STUDY 6

A young person asks to limit parental access

Sheldon is 15 years old. Sheldon and his parents currently have full access to Sheldon's clinical records via a patient portal. Over the last month, Sheldon has been experiencing feelings of worthlessness and guilt. He is usually an 'A' grade student, but his school performance has deteriorated. He seeks your help about his feelings and requests that his parents are not given access to the clinical records about this aspect of care. What do you do about portal access?

In this scenario, consider the following:

- Sheldon's maturity and understanding (whether *Gillick* competent)
- Sheldon's views on privacy and confidentiality, including his views on disclosure of health information to his parents
- the nature of the health information (eg sensitive, personal information)
- whether it is in Sheldon's best interests to disclose the information
- Sheldon's health condition
- whether disclosure is likely to harm Sheldon's health
- the rights of access that his parents have as his representatives.

Firstly, determine whether Sheldon's request to withhold parental access is genuine. His request should be talked through with him so that his concerns are understood.

Sheldon may be assessed as having sufficient understanding and maturity (*Gillick* competent) to give his informed consent to care. Consequently, treatment may proceed without obtaining parental consent, and Sheldon's parents would not require the information for the purposes of providing consent. However, if it is appropriate in terms of Sheldon's safety and support needs, he should be encouraged to involve his parents or other trusted adult to assist in the management of his health condition. The more serious or complex a health issue is, the more likely the support of a caring adult will be required. A youth health practitioner or Māori and Pacific community health worker could be involved in these discussions, if appropriate.

Some or all of the health information about Sheldon may be withheld by exercising judgment, taking into account his situation. As the patient portal allows ongoing access to Sheldon's clinical record, the options include:

a. Withholding some information via portal access:

GPs have the ability to mark items as confidential on the PMS, and this information will not be uploaded from the PMS to the portal. In this case, if notes on

the current consultation are marked confidential, then this information will not be visible via the patient portal to Sheldon or his parents, even if they have shared portal access.

The confidential information could then be supplied to Sheldon by other means, eg paper copy of the relevant record.

b. Restricting portal access to all clinical records:

Sheldon may choose to opt out of having shared portal access. If you decide to discontinue Sheldon's parents' access to his patient portal, the options include:

- creating a new account for Sheldon using a new email address as Sheldon's unique identifier (and for Health365, disabling the parents' access to his record).
- asking Sheldon to change his log-in credentials (ie his password for portal access), which is withheld from his parents.

Tensions may arise between Sheldon and his parents as a result of restricting portal access, and his parents could pressure him to divulge his log-in credentials. However, these tensions could be minimised if issues of confidentiality and a future shift in control over the portal had already been discussed at early adolescence. A youth health practitioner or Māori and Pacific community health worker could be involved in these discussions.

c. Closing the patient portal:

A last resort is to close Sheldon's patient portal and supply the requested clinical records to Sheldon in paper form. However, portals may provide more than a means to access clinical records. Patients can interact with their general practice team to book appointments, request repeat prescriptions, and undertake secure communication. Therefore, the issues should be worked through with the aim of making the portal work in this case.

APPENDIX 1

Legal considerations

Health Information Privacy Code

Rule 6: access to personal health information

All individuals, including young people, have the right of access to their own health information. There are limited reasons for refusing a request, such as if, in the doctor's judgement, the disclosure of the information would be against the young person's interests (s 29(1)(d) of the Privacy Act 1993), or where the disclosure would involve the unwarranted disclosure of another's affairs (s 29(1)(a)).

Rule 11: disclosure of health information

Rule 11 allows disclosure of health information about young people in specific circumstances. For example:

- if the disclosure is one of the purposes in connection with which the information was obtained (such as where information is required by another health provider for further treatment) (rule 11(1)(c)), or
- where it's not practicable to get the young person's permission, and disclosure is not against the wishes of the young person and is in line with recognised professional practice (rule 11(2)(b)).

Parents of young people under 16 years have the right to access their young person's health information and to receive it, unless the disclosure would be against the wishes or interests of the young person (s 22F Health Act 1956, see below).

Informed consent and competency

Informed consent is a process comprising a number of elements, including competence, provision of information, understanding, voluntariness and consent.

There are two approaches to deciding competency for the purposes of consent to treatment – status and understanding. Firstly, under the Care of Children Act 2004, a young person 16 years or over may consent to health care (and females younger than 16 may consent to abortion). Secondly, if no specific statutory provisions apply, the legal position is governed by the Code of Health and Disability Services Consumers' Rights (the HDC Code) and common law – the 'maturity' approach. A young person of sufficient maturity, even if under the age of 16 years, may consent to treatment. This approach follows the case of *Gillick v Wisbech Area Health Authority* [1985] 3 A11 ER 402, which established the 'Gillick competency test' for determining when a minor is competent to consent to medical treatment.

Minors may authorise medical treatment if they are mature enough to understand what is proposed and are capable of expressing their own wishes.

Capacity to give consent is assessed for each situation, taking into account the age of the young person, their functional maturity, the complexity of the information being given, the seriousness of their medical condition and the implications for the young person of treatment and non-treatment. In making this assessment, it is helpful to ask whether the patient is capable of understanding what is proposed (reasons for, nature, probable benefits, risks and alternatives of the intervention) and of expressing their own wishes.

Informed consent and disclosure of health information

Every consumer, including a young person, has the right to the information that a reasonable consumer, in that consumer's circumstances, needs to make an informed choice or give informed consent (Right 6(2) of the HDC Code). Even if a young person is not mature enough to give a valid consent, they have a right to receive appropriate information at the level of their understanding with a full explanation made to the young person's parent or guardian.⁷

Under Right 7(1) of the HDC Code, services may be provided only if a consumer chooses and gives informed consent to those services, except where the law provides otherwise. Valid choices cannot be made and valid consent cannot be given by someone who does not have sufficient information.

Rule 11 of the HIPC allows disclosure of information if disclosure is one of the purposes for which the information was obtained (even without consent for disclosure). Disclosing information to ensure the proper exercise of informed choice and informed consent to provide appropriate treatment are such purposes for disclosing information under rule 11 of the HIPC.

Where a young person lacks the capacity to consent to treatment, consent may be sought from their parent or guardian, and the information necessary to enable a parent or guardian to give informed consent should be disclosed to them. The law provides the flexibility to disclose information to a parent or guardian who is giving consent to treatment of a young person.

A young person or their parent should usually be made aware of the purpose of collecting information at the time the information is collected (rule 3 of the HIPC and principle of openness). This may include making a young person aware that some information will be disclosed to their parent if the parent will be asked to give informed consent. This disclosure is an anticipated disclosure because the need to disclose information was anticipated at the time the information was obtained. The HIPC does not require consent for this disclosure.

Non-consensual disclosure of information

The more difficult problem arises when the need for disclosure has not been anticipated. For example, where disclosure has not been authorised by the individual concerned, or if the disclosure of information is not one of the purposes for which the information was obtained.

Specific legislation may require non-consensual disclosure. For example, health professionals and carers dealing with a patient may ask anyone for access to health information about the patient under s 22F of the Health Act 1956.

A young person's representative (ie parent or guardian) is entitled to request access to the health information of those under the age of 16 years. However, there is discretion to refuse a request where the young person does not wish the information to be disclosed, where disclosure would be contrary to the young

person's interests (rule 11(4) of the HIPC), or where another withholding ground applies (ss 27–29 of the Privacy Act 1993).

Once a young person turns 16 years, a parent or guardian has no special right to access their health information. However, GPs may give health information to a principal caregiver or near relative where it is not practical or desirable to get the patient's permission (eg they are very unwell or not competent) and the patient has not vetoed the disclosure (rule 11(2)(b) of the HIPC).

Disclosing information about young people, whether by way of a patient portal or otherwise, is generally at the discretion of the GP involved. When exercising this discretion, the following factors should be taken into account:

- The understanding and maturity of the young person
- The nature of the health information (eg sensitive, personal information, information about another individual)
- The young person's health condition
- Whether access would harm the young person's physical or mental health
- The young person's views on disclosure
- The purpose for accessing the information
- The rights of access that the parent has as the young person's representative
- The young person's living arrangements
- The relationship between the young person's parents and any custody arrangements.

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