

Tandem Member Consultation 24.06.21 Summary of Themes & Responses

Twenty-four members participated in our consultation on the new Act. In response to the Victorian Department of Health's 'Update and Engagement Paper', the following questions were asked of members, and these responses and themes emerged.

Q1) Please provide a list of the categories or types of information you feel services should provide to families, carers and supporters where the consent of the person is not required?

Q2) At what points in the person's recovery journey do you think information should be shared with families, carers and supporters?

Q3) In what circumstances and for what reasons should information be shared with families, carers and supporters regardless of consumer consent?

Question One:

The types of information members felt should be shared with families, carers and supporters regardless of the person's consent fell into the following categories:

- General information
- Legal and rights information
- Service information
- Diagnostic information
- Information about treatment and recovery
- Information and education to support the caring role
- Safety information

Categories	Types/examples
General information	<ul style="list-style-type: none">• E.g.: information about nominated persons and advanced statements.
Legal and rights information	<ul style="list-style-type: none">• E.g.: carer rights and clear information about confidentiality and privacy.
Service information	<ul style="list-style-type: none">• Family/carer specific service and support information: including services available to support family/carer wellbeing, practical support, advocacy services, service navigation and access information.

	<ul style="list-style-type: none"> • General information about the service (particularly at point of entry); and including service and staff contact details for family/carers to make contact. <p>Additional comments included that this be a consistent service contact person for family/carers to discuss concerns if the person is deteriorating, for example, and making this a duty of providers or the designated service person to actively engage with family/carers.</p> <ul style="list-style-type: none"> • Information about how the service works with families/is family-inclusive, including learning and development training for staff.
Diagnostic information	<ul style="list-style-type: none"> • Informative and educational information about the diagnosis, including causes, how it gets reached, associated symptoms and signs, treatment options available, information about comorbidities (e.g.: substance use), and resources to assist families.
Information about treatment and recovery	<ul style="list-style-type: none"> • Information to families about the broad treatment plan. • Additionally, information about medication, such as possible side-effects and what to look out for. • Information about treatment options and recommendations. • Relapse prevention and indicators for relapse. • Recovery plans and recovery goals of the person; inclusive in recovery planning, exchange around family/carer goals and strategies to maintain their own wellbeing. • Symptom management (being general and informative), as well as further educational options and resources available for families. • Families to be informed when seclusion and restraint is being used/considered.
Information and education to support the caring role	<ul style="list-style-type: none"> • How families/carers/supporters can provide care and support to the person (strategies to use and how to get help)

	<ul style="list-style-type: none"> • Any helpful information family/carers can have to support the person if not responding to treatment or at risk of disengaging (including communicating signs the person is at risk of disengaging or when they have disengaged). • Responses around information to support the caring role from time of discharge (how to support the person by way of symptom management, helpful strategies, signs of relapse, what to do if mental health deteriorates; and information on integrated supports (e.g.: housing), and broadly any information that will impact the carer). • Responses concerning safety and risk (families to be informed of changes in risk levels and provided any information and support to manage situations, including regular mental health updates).
<p>Additional comments/themes</p>	<p>Information sharing as two-way; positive exchange, with a strengths-based language approach</p> <ul style="list-style-type: none"> • Being able to share information about the person <i>with</i> service providers ('What <i>I</i> can share'). • A positive two-way exchange between service provider and family member/carer (not just simply saying 'I can't talk to you'). • A strengths-based language approach in information exchange, and a focus on wellbeing.

Members emphasised the importance of being able to share information about the consumer *with* service providers; that information sharing be not seen as solely dependent on what services will or won't share with family members/carers/supporters.

Using a strengths-based language approach in information exchange with families/carers/supporters was further highlighted; the framing of information shared in a positive way, with a focus on wellbeing, can assist with bridging the relationships.

Question Two:

Members identified the following points or stages in the consumer’s treatment and recovery journey where they felt information should be shared with families, carers and supporters. Broadly, members felt key points or stages included *early* in the person’s treatment and recovery journey as well as during *periods of change* in the person’s journey. More generally, members felt information should be shared ‘ongoing’, ‘early and often’, ‘at all points’, ‘key stages and milestones’ across the journey.

Theme	Responses
<i>Early in the journey</i>	<ul style="list-style-type: none"> • At service entry/first point of contact between service and consumer • When treatment starts/at the early stages of treatment • When a diagnosis is made
<i>At/during points of change in the person’s treatment and care/mental health and wellbeing</i>	<ul style="list-style-type: none"> • When the person is, or is becoming, unwell/is at-risk of harm to self and/or others (including family members) • When treatment changes • At admission • During inpatient stays • When the person transitions to another service • When the person disengages from a service/is at-risk of disengaging • When seclusion and restraint (including chemical restraint) is being used • At point of discharge (particularly if the consumer is being discharged to the family home), pre-discharge/discharge planning stage, and post-discharge (during follow-up care)
<i>Often and ongoing</i>	<ul style="list-style-type: none"> • At all points/stages of treatment and care • As early and as often as possible across the recovery journey • When and as often as the carer seeks (to be truly person-centred) • At all key stages and milestones

Question Three:

**Responses and themes relating to this question were covered in Q1 and Q2.*